SOCIAL SUPPORT

Social Support: Section Introduction

Martin McKee, David Chinitz, Rachel Nissanholtz

Over the last few decades, health systems worldwide, spurred on by the need to contain costs, have engaged in structural reforms of their health systems. This has led to burgeoning comparative literature as reforms, many market-based, have been studied in a quest to learn from the experience of others. Despite some voices to the contrary (Saltman, 1998), the tendency has been to look horizontally at elements that seem comparable, such as financial incentives, outcomes measurement, and even citizen participation. Less has been focused on trying to systematize what Saltman has called “social embeddedness”. The contextual issues, such as core values, national culture, and professional norms, are, relative to the “harder” elements of structural reform, difficult to quantify and harder to regulate and manage. But they are crucial to success of health policy implementation.

The Social Support track of the conference was dedicated to the insight that we have reached a stage in the development of health systems that calls for increased focus on some intangible inputs. These intangibles have not been ignored in the past, but they have often been placed in the “too difficult” tray and attempts to manage them have lagged behind treatment of the more tangible, especially economic, aspects of health systems. Optimal deployment and management of mechanisms of social support might be expected to contribute to responsibility and accountability. Our expectation, largely met during the conference, was that the papers presented would focus on the following issues:

- How can we promote a better understood and better managed interface between factors such as social solidarity, culture, and institutional frameworks on the one hand, and on the other, technical tools such as financial incentives, outcomes measurement, and legal mandates in policy making in health systems?

- How can we avoid the danger that technocratic interventions will vitiate social and cultural norms important to the viability of health systems?
- How can the health system interact with other social systems in order to promote health, decrease inequalities, and contribute to economic growth?
- What are the roles of social networks, civil society, provider networks, and other non-governmental structures, in strengthening social support for the activities of health systems?
- To what extent can we rely on trust in regulating and managing health systems?
- How can we improve public understanding and increase the quality of public debate on health policy and management?

It was gratifying to see how the presentations provided evidence of behavior that blends financial, professional, and epidemiological inputs with social solidarity. Examples included the papers by **Ran Balicer et al**. and **Rachel Wilf-Miron et al**. that describe the self-initiated programs of two Israeli HMOs to tackle health inequalities, even though such inequalities are influenced as much, or more, by factors outside the control of the HMOs. Similarly, the papers by **Leon Epstein** and **Rosalind Raine** reflect the need to bring together a diverse array of inputs and perspectives in order to address inequalities at the national level.

Interactions between individuals and health care providers frequently occur at transitions in life, such as birth, death, or illness. Often these transitions have important cultural dimensions, and several papers reported on attempts to make services more culturally accessible to specific disadvantaged populations. These include the paper by **Nurit Guttman and colleagues** on ensuring that Ethiopian immigrants to Israel receive information on health rights that truly addresses their needs and interests, as well as being in a format that is accessible to them. The paper by **Nihaya Daoud, Ilana Belmaker, and Ilana Shoham-Vardi**, turns our attention to another culturally unique group in Israel - the Bedouin, and explores the role of maternal beliefs, culture, and material characteristics in determining the timing of visits for well-baby care.

Another dimension addressed at the conference, though not reflected in the set of papers in this volume, was the role of family caregivers and their interface with formalized institutions in improving quality of care to, for example, stroke patients. Several of those papers explored how to ensure that formal and informal care function as mutually supportive complements, rather than substitutes.

Notwithstanding some of the favorable and optimistic developments reported, the papers raised dilemmas, some of which echoed the track on personal responsibility. Some of these issues are explored in **Eric Brunner**'s paper regarding a working definition of morality in public health, which seeks to extend beyond Rawls' difference principle and take account of the special role of health in determining who is "the least well off in society". Other conference papers, not included in this volume, noted that some communities with strong social solidarity, such as ultra-religious communities in Israel, are characterized by better health indicators despite lower socio-economic status. Does this outcome place more (or less) accountability on such communities for the health status of their populations? If informal care givers step forward to provide care to their loved ones, does this relieve the government of responsibility and accountability? What implications does this have for those who do not live in groups with these characteristics? The plenary session anticipated these issues and provided a sobering view of the tenuous relationship between health policy and social solidarity. **Martin McKee**, in his plenary presentation, described the threats to solidarity from social upheaval, such as large scale immigration, and from well-organized reaction to government intervention in health systems. The swinging of the pendulum between government and private responsibility and accountability needs to be supplemented with new approaches, such as "shared responsibility", to borrow a phrase suggested by Richard Scheffler at the end of the plenary session. **David Chinitz** proposed that we move from a world of "legends" regarding the hegemony of technical structural health policy and management, to one in which we not only account systematically for softer, social, aspects, but even seek to influence them.

The role of social networks, civil society, provider networks, and other non-governmental structures, in bringing social support to bear in the behavior of health systems is explored in the papers by **Larry Brown** and **Karen Feinstein et al.**, with Larry's paper focusing on the role of community groups at the local level, and Karen's paper focusing on the role of provider/insurer collaborative at the regional level.

An approach that can facilitate such shared responsibility is the sharing of information and discussion between decision makers and the public. A number of conference presentations, not included in this volume, dealt with the divergence of opinion between these two groups on issues of health care priority setting and allocation of resources to alternative uses, such as high technology fertility treatments. The continuing monitoring of public knowledge about and attitudes towards health policy decisions and dilemmas can strengthen public debate necessary for maintaining responsibility and accountability in the health system.

Building on nascent programs aimed at narrowing health inequalities, evidence was presented that strengthened cooperation among sectors (such as formal and informal care) and improved public understanding can contribute to maintaining social solidarity in health systems. The next challenge for health policy and management is to weave together new, inter-sectoral institutional innovations, based on epidemiological data, evidence-based medicine, and surveys of public knowledge and attitudes.. Moving beyond reliance on technical tools to systematize the analysis and management of social support mechanisms essential for successful health system performance is the order of the day.

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Reducing Health Inequalities in Clalit Health Services: From Vision to Reality

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Introduction

Clalit Health Services, Israel's largest health fund with over 3.8 million enrollees (53% market share) has a significant overrepresentation of the underprivileged: low socioeconomic groups, minorities, new immigrants, residents of rural areas, the elderly, and people with disabilities (Horev & Kop, 2008). Over the years, Clalit has gained experience in comprehensive quality improvement programs (Goldfracht & Porath, 2000; Peleg et al., 2008), as well as in sporadic efforts directed at improving the health status of the disadvantaged groups (Maislos, Weisman, & Sherf, 2002; Nirel, Pilpel, & Rosen, 2000).

In 2007 Clalit laid out its first organization-wide strategic plan to reduce inequalities in health and health care. The strategy builds on the strengths of the existing infrastructure, including a unique data warehouse that contains detailed "cradle to grave" data (demographic, health indicators, and health care services utilization data); a large primary care-public health oriented workforce in the local communities; and an extensive set of quality measurement and management tools based on data from a universal system of electronic medical records.

The strategy employs both a top-down approach of disparity-reduction goal setting, continuous monitoring and provision of incentives; and tailored interventions to reduce disparities by a bottom-up approach in which each district and locality is empowered to plan interventions, policy changes, and shifts in workforce. Findings on the initial implementation efforts and their results are presented.

The Disparity Reduction Strategy – Overview

Clalit's existing quality improvement processes were, to the point of the initiation of the disparity-reduction strategy, generic. The new strategy, aimed at closing quality gaps and not merely achieving improvement, began with the development of a set of targeted indicators to serve as the target-setting tool.

A panel of physicians, nurses, and senior public-health professionals examined the 70 health care quality indicators currently used at Clalit as part of ongoing quality measurement and improvement processes, to determine their inclusion as disparity indicators. Data on percent attainment of each indicator were based on annual percent attainment recorded during the second quarter of 2008. In the first phase of the selection process, the 70 indicators were ranked by level of disparity between high and low socioeconomic populations within Clalit. Indicators that met the following criteria were selected: (1) the high-to-low SES ratio was above 1.1 (more than 10% difference), (2) reflect evidence-based high impact medical care, (3) pertain to large segments of the population in various age groups, (4) focus on prevention (primary and secondary), and (5) are representative of processes and outcomes of care.

This process resulted in the selection of seven indicators: (1) Diabetes control: Percent of patients with HbA1c <9%; (2) Blood pressure control: Percent of patients with blood pressure at or below 160/100 mmHg; (3) Lipids control: Percent of patients with LDL < 100 mg/dL; (4) Anemia in infants: Percent of infants age 9-18 months with hemoglobin above 105 g/L; (5) Influenza immunization rate: in target populations (>65 years of age or chronically ill); (6) Mammography test rates, once every 2 years for women aged 50-75; and (7) Occult blood tests: once every year for persons aged 50-75. A composite weighted performance score, termed the Quality Indicator Disparity Scale (QUIDS), was constructed to reflect attainment of all selected indicators. All 381 medium-large clinics (providing care to 60% of Clalit's enrollees), serving about 2.2 million persons, were rated on the QUIDS.

Fifty-five low performing clinics, which serve 10% of Clalit's total population (~400,000 enrollees), were selected for the project. As expected by the selection process, target clinics were significantly more likely to serve patients of low SES and to be clinics serving minority populations. Some clinics serving underprivileged populations, however, were high performers – in QUIDS score and in most other quality measures.

After the selection process was set, a district steering committee at each of Clalit's eight districts reviewed the lists and ascertained that the selection of clinics was indeed representative of the main foci of quality care disparities in the district.

Setting Goals and Incentives

At each district a steering committee formulated a plan for quality improvement and disparity reduction. Three key types of interventions emerged: enhancement of teamwork and local leadership, improved access to services, and development of cultural competency programs. Teamwork and local leadership interventions include: enhancement of managerial and leadership skills, and designation of key personnel to lead improvement in the target indicators. Improved accessibility initiatives include: increasing access to preventive services (e.g., mobile mammography units) and outreach initiatives to identify and summon patients for recommended preventive and follow-up services. Cultural competency interventions, including translation and cultural mediators' services and involvement of religious leaders in tailoring culturally appropriate health promotion messages.

A comprehensive evaluation process to collect detailed data on the interventions employed by each target clinic was initiated. Districts' steering committees and target clinics were asked to complete case-study reports on the features of each intervention. This detailed evaluation is currently ongoing.

Initial Results

The average change in QUIDS score for July 2008-June 2009 indicated a significant reduction in the gap. Target clinics improved at a faster rate than all other medium-large clinics, while overall quality scores continued to improve in all non-target clinics. The average difference in QUIDS score between the target clinics and all other clinics remained constant between June 2008 and December 2008. The organization-wide project was initiated in September 2008 and measurements in January 2009 began to show the effect of the locally tailored interventions. During the first two quarters of 2009 the average difference in QUIDS score narrowed considerably; at 6 months, a 30% reduction in the QUIDS difference between the targeted clinics and other clinics at the district was achieved. Total gap-closure rates ranged from 17.5% to 81% for each of the eight districts.

Discussion

This strategy is unique in that it presents a large-scale organization-wide systematic process of disparity reduction based on a quality improvement approach (Fiscella, 2007; General Accounting Office, 2003). Previous studies have shown the benefits of organization-wide quality improvement strategies (Ornstein et al., 2008), yet universally applied quality improvement efforts do not necessarily reduce disparities (Sequist, Adams, Zhang, Ross-Degnan, & Ayanian, 2006; Trivedi, Zaslavsky, Schneider, & Ayanian, 2005), as strong populations tend to absorb the interventions earlier and to a larger extent, potentially increasing the care quality gap. The strategy presented here aimed to overcome this barrier by implementing a dual approach of focusing organizational efforts on the most challenged clinics.

The initial results of Clalit's disparity reduction strategy show that reduction of disparities can be achieved by employing an organization-wide plan that combines top management leadership and support; measurable targets for disparity reduction; and multi-component interventions, including culturally tailored quality improvement and local solutions for local challenges in improving access to and utilization of services; ongoing monitoring, assessment, and cross-organizational learning.

Acknowledgments

Special recognition is given to all members of the Health Disparity Reduction Steering Committee for their roles in strategy development and consultation throughout the process. Our utmost appreciation goes to all district and local teams for their key roles in planning and implementation.

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From Measurement to Comprehensive Policy: The Action Plan of Maccabi Healthcare Services to Increase Equity

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Introduction

The commitment to promote equity in health care is derived from the notion that all humans deserve to achieve the best health, since health is a basic human right (UN, 1948). The adoption of the United Nations' declaration by the WHO in 1978 (WHO, 1978) set this goal as a moral foundation for governments and health organizations.

Inequity in health is defined as "the presence of systematic and potentially remediable differences in one or more aspects of health across socially, demographically, or geographically defined populations or population sub-groups" (ISEQH, 2000). These differences are not only unnecessary and avoidable but, in addition, are considered unfair and unjust (Whitehead, 1992). Despite these declarations and good intentions, disparities in access to health care services and health outcomes, based on ethnicity and socio-economic status, has been well documented in recent years around the world (Institute of Medicine, 2003; Long, Chang, Ibrahim, & Asch, 2004; Mayberry, Mili, & Ofili, 2000; Thomas & Quinn, 2008; Wong, Shapiro, Boscardin, & Ettner, 2002) and in Israel as well (Baron-Epel, Garty, & Green, 2007; Endevelt, Baron-Epel, Karpati, & Heymann, 2009; Epstein, 2007; Manor, Eisenbach, Friedlander, & Kark, 2004). The evidence regarding disparities among Israeli sub-populations and vulnerable groups are striking based on the fact that Israel has a universal health system under a National Health Insurance Law. Our health system provides primary, secondary, and tertiary services largely free of charge with a broad benefit package of services.

The Institute of Medicine (IOM) has suggested that the quality of health care is defined - among other dimensions - by the care being equitable, i.e., care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status (IOM, 2001). The inclusion of equality as a dimension of quality means that health organizations can no longer define their quality only by good performance "on an average", but are also committed to reduce health disparities among their beneficiaries.

Maccabi Healthcare Services (MHS) is the second largest Israeli HMO, providing community-based services to 1,800,000 members that represent diverse population groups. Care is delivered in five regions with 150 branches throughout the country.

Since 2004, MHS has operated a computerized system named Health Value Added (HVA) to manage care improvement according to measurable goals. Thirty indicators represent six clinical domains, including early detection of breast and colorectal cancer, influenza and pneumococcal vaccination, diabetes follow-up and control, and care for cardiovascular disease (CVD). For each indicator, an organizational benchmark is set, from which annual goals are derived for the units (regions and branches). Achieving the goal is followed by recognition and a modest reward. This system produces monthly reports to managers and caregivers describing actual performance, and the proportion of the goals that have been met for each indicator. This ongoing quality measuring and reporting exposed MHS's managers to the disparities existing between branches that serve different population groups. Gradually, the equity issue became part of the managerial discourse. As a result, field staff started to analyze barriers to care and to implement tailor-made solutions to reduce disparities. One example is the intervention to increase mammography screening rates among Arab women that took place in 2004-2005 and was part of an organizational-wide effort to improve screening. A local team of three branches, known as the "Triangle" (El-Tira, Kalanswa, and Teibe), identified unique barriers to utilization of breast screening services such as social norms that prevent women from traveling by themselves to the screening facility, and language barriers. The team initiated a special program that provided solutions to the identified barriers. The quality improvement infrastructure helped in organizational learning and generalization of the lessons to all branches that serve the Arab population. In a 15-month period, screening rates in the Arab population increased from 26.7% to 46.2% (73% improvement), while overall MHS screening rates increased from 49.0% to 63.1% (29% improvement). This and similar experiences became a well known “story” in the organizational repertoire and gradually led to the understanding that change is feasible.

Recently, the Israeli public has been exposed to data on the widening of disparities in Israeli society, including its effect on health care. This served as another trigger for MHS to deal with equity issues.

In 2008, MHS management decided to implement a long-term and comprehensive strategy to promote equity and equality in care provision as well as health outcomes. As the first step, it was decided to produce an in-depth analysis that would identify populations at risk for disparities in health outcomes. The results of these studies aimed to serve as a foundation for organizational policy decisions to promote equality.

This paper describes 1) the First Equality Report, published in June 2009, which summarizes the first analysis conducted and the resulting recommendations; 2) the organizational process to create a consensus on the set of recommendations; and 3) the action plan that MHS has adopted.

The First MHS Equality Report

This report summarizes the analysis of associations between health measures and the demographic and socio-economic characteristics of MHS members.

Methodology

Data were extracted in November 2008 (due day) from the HVA computerized system with additional information gathered from the MHS billing system and the Israeli Census (Israel Census Bureau, 2007). The analysis included all MHS adults 18-80 years of age, who had visited their general practitioner at least once during the previous two years. Data were gathered for selected indicators, and for each of them information was obtained for the previous 12 months.

Dependent Variables

A. *Prevalence of Diabetes and CVD*

B. *Process and Intermediate outcome measures in diabetes and CVD care*

C. *Prevention and early detection: Pneumococcal vaccination, and breast and colorectal cancer screening.*

These indicators were chosen to reflect the major indicators that MHS measures on a regular basis at the regional and branch level (the HVA system).

Independent Variables

Socio-economic status, Ethnicity (Arab, Jewish), Immigration status (immigrants, veterans), Complementary health insurance, and geographical region.

Definitions

Dependent Variables

Diabetes: All eligible MHS adults who were registered in MHS Diabetes Registry (DR) (Chodick, Heymann, Shalev, & Kookia, 2003).

Heart Disease: All eligible MHS adults who were registered in the Cardiovascular Disease Registry (CVD) (Chodick et al., 2010).

Performance measures

Optimal follow up: DR patients who, during the previous year, performed all of the following tests at least once: blood tests for LDL Cholesterol, HbA1C, urine micro-albumin, eye and foot examination, blood pressure and Body Mass Index recording.

Intermediate Clinical Outcomes

A. Diabetes Control: All eligible MHS diabetic adults who were registered in the DR on the due day, performed HbA1C testing in the previous year and achieved a result of HbA1c < 7.00 gr%.

B. Poor diabetes control was considered when HbA1C test results were > 9.00 gr%.

C. CVD control: All eligible MHS adults registered in the CVD registry who performed LDL Cholesterol testing during the previous year.

Prevention and early detection

D. Pneumococcal vaccination: all MHS eligible members who were ever vaccinated after the age of 65, or in the previous five years if the vaccine was provided to adults younger than 65 years of age.

E. Mammography screening: all MHS eligible women aged 52-74 free of cancer who performed at least one mammography examination during the previous two years.

F. Colorectal cancer screening: all MHS eligible adults aged 51-74 free of cancer who performed fecal occult blood tests during the previous year or at least one colonoscopy during the previous five years.

Independent Variables

A. *Socio-economic status:* MHS members were categorized by socio-economic rank (SER) according to the grading of Israeli sub-districts on a 1-20 scale (1 - lowest, 20 - highest) using their home address (Israel Census Bureau, 2007).

B. *Ethnicity:* Since personal data on ethnicity is not available at the HMO level, Israeli Arabs were identified by the ethnicity of their settlement as recorded by the Israel Census Bureau (2007)

C. *Supplemental Health Insurance (SHI)*: Israel has a universal health care system with a unified benefit package of services provided by the four HMOs. All HMOs offer their members a private SHI for services that are not included in the basic package.

D. *Immigration:* Most of the immigrants in our data set were adults who immigrated to Israel from the Former Soviet Union countries since 1989. Therefore, this definition of an immigrant was adopted for analysis.

Statistical methods: Age-adjusted rates, rate ratios, and 95% confidence intervals (95%CI) were calculated. For the direct adjustment, the entire MHS population or the relevant registry population served as reference.

Main Findings

Socio-economic Ranks (SER): 9% of the Maccabi population belong to the lowest SER categories (1-5), while 26% belong to the highest (16-20).

Of the five MHS regions, the northern and the southern regions, considered the Israeli periphery, have higher rates of members belonging to the lowest SERs and higher rates of immigrants, compared to other MHS regions. Two-thirds of the Arab members in MHS belong to the northern region, while the southern region is characterized by the highest rate of poor members compared with other regions.

MHS members who belong to the lowest SERs have presented with greater prevalence of chronic illness (diabetes and CVD), and lower rates of diabetes control and early detection of colorectal cancer compared to members from the highest SERs. Diabetes was 1.4 times more prevalent in men and 2.1 times more prevalent in women from the lowest SERs compared to those from the highest SERs (Figure 1). CVD was 1.2 times more prevalent in men and 1.6 times more prevalent in women who belong to the lowest SERs compared to those who belong to the highest SERs. Poor diabetes control was twice as common in females from low SERs compared with high SERs (Figure 2). Screening for colorectal cancer was half (57%) as common among male members who belong to the lowest SERs compared to those in the highest SERs. Disparities in mammography screening among different SERs were relatively small (Figure 3).

Figure 1: *Diabetes prevalence (%) by SER, adjusted for age.*

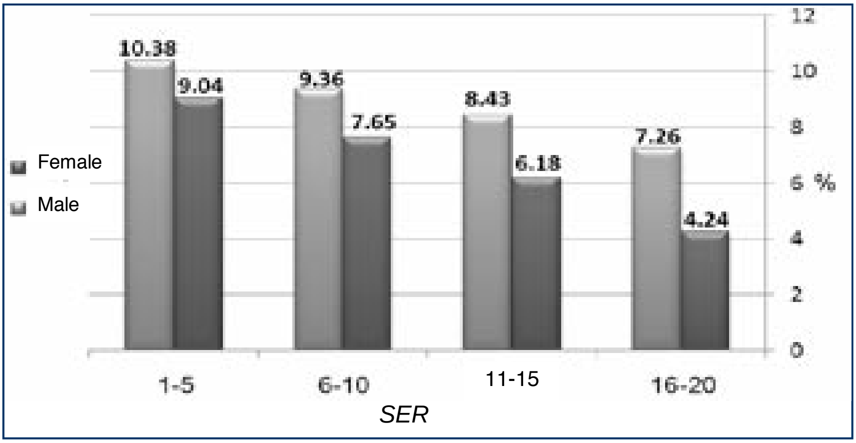


Figure 2: *Percent of patients with poor diabetes control (HbA1c>9 gr%) by gender and SER, adjusted for age.*

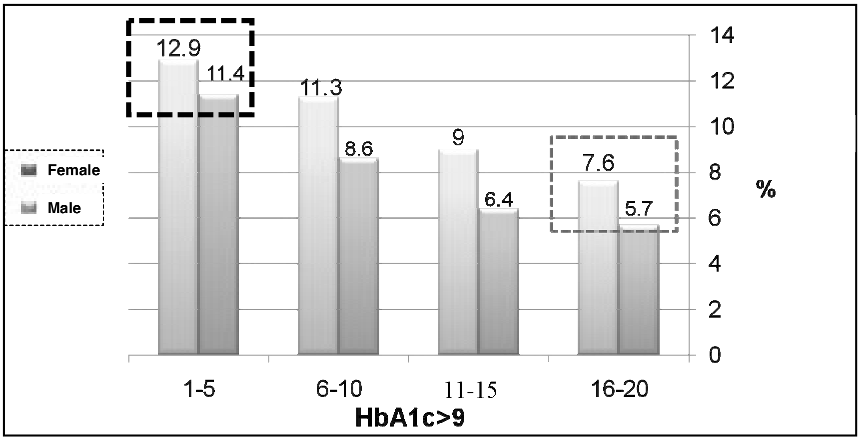
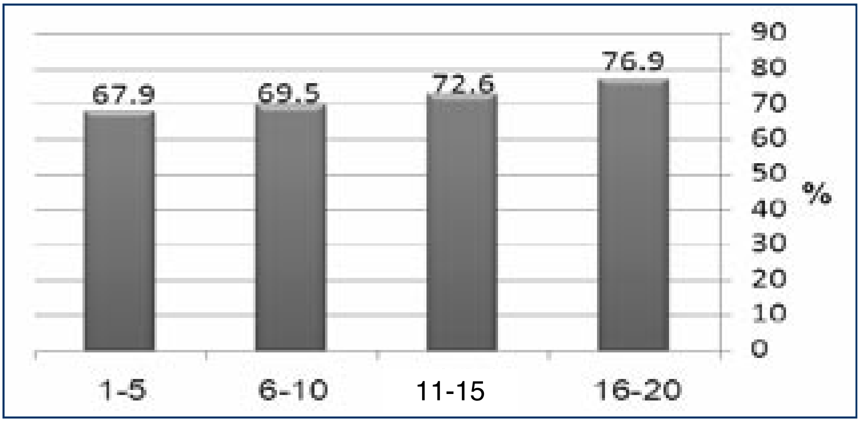


Figure 3: *Mammography utilization among women aged 52-74 by SER, adjusted for age.*



Ethnicity

Analysis revealed disparities between Arabs and non-Arabs in most health measures. Prevalence of diabetes is greater in Arabs compared to non-Arabs, especially among the females. Optimal follow-up for diabetes was similar among the two ethnic groups. Arab females achieve less favorable diabetes and CVD control. While comparing Arabs and non-Arabs belonging to the lowest SERs (1-8), disparities usually diminish but do not disappear. For example, the rate ratio of Arab to Jewish females achieving poor diabetes control is 2.22 among the overall population and 1.49 among the poor (Table 1).

Immigration

Fifteen percent of MHS members are new immigrants from the Former Soviet Union countries. No robust differences were found between immigrants from the Former Soviet Union countries and Israeli veterans after controlling for SER and geographic regions.

In some health measures, such as diabetes control, immigrants achieved better results when compared with veterans, after controlling for age and SER.

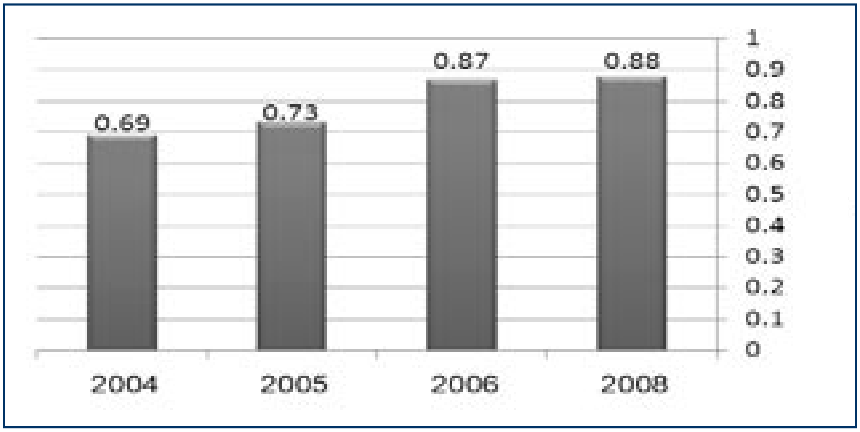
Table 1: *Rate ratios (Arabs vs. Non-Arabs) by Gender and SER Adjusted for age.*

	SERs 1-8 Total Population			
	Male	Female	Male	Female
Diabetes Prevalence	1.52	1.79	1.20	1.27
CVD Prevalence	1.16	1.37	1.47	1.11
Diabetes				
Performed HbA1C test	1.01	1.05	0.99	1.02
Performed LDLC test	0.99	1.01	0.98	0.99
Performed Optimal F/U	0.90	0.93	0.80	0.83
Achieved HbA1C<7gr%	0.74	0.75	0.81	0.78
Achieved HbA1C>9gr%	1.79	2.22	1.37	1.49
CVD				
Performed LDLC test	1.09	1.20	0.91	1.00
Prevention in Healthy Members				
Performed LDLC test	0.94	0.98	0.98	1.00
Colon cancer detection	0.64	0.78	0.83	0.94
Mammography		0.88		0.93
Pneumococcal vaccination	0.93	0.96	0.98	1.00

Supplemental Health Insurance (SHI)

Eighty-seven percent of MHS members own SHI. Ownership of SHI is more common among members from the higher SERs compared to the lower SERs. Ownership of SHI was associated with better performance in most measures. It is important to note that although mammography is offered free of charge to women aged 52-74, and is relatively easy to perform, the performance of this exam, for example, was 2.2 higher in SHI owners comparing to non-owners (Figure 4). This suggests that SHI is not the cause of disparities but rather a marker of undefined socio-demographic variables and health behaviors that are associated with less favorable health outcome.

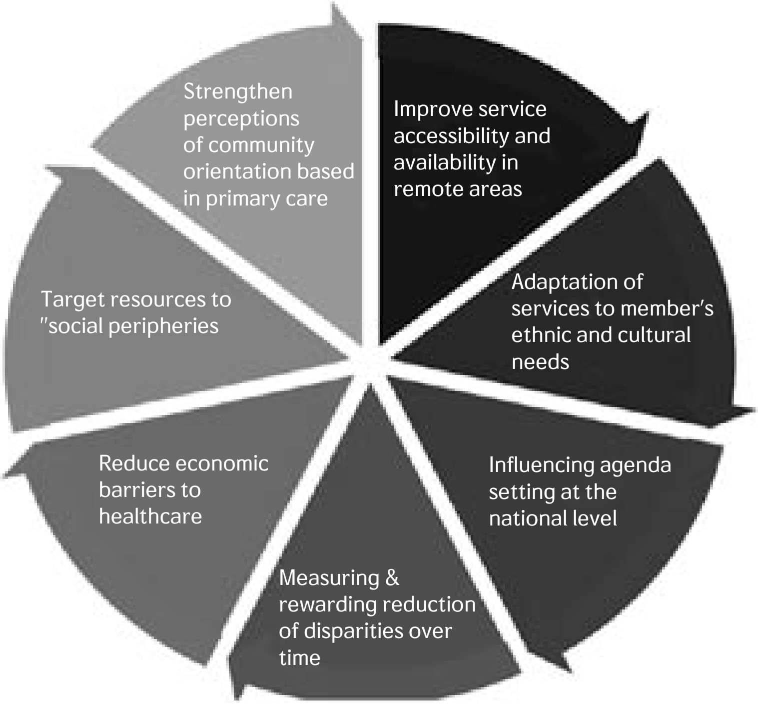
Figure 4: *Rate ratios of mammography utilization: lowest to highest SER, by year.*



The Organizational Process to Create a Consensus over a Set of Recommendations

The analysis results summarized in the First Equality Report were followed by a set of recommendations that were directed to reducing disparities and promoting equity and equality. MHS is a provider of health care services and thus bears responsibility not only to recognize disparities but also to take actions to tackle them. Therefore, these recommendations had to be translated into operative decisions. In order to gain a broad consensus of these steps, it was decided to expose managers both in the field and in the central administration to the findings of the report and to lead a dialogue over the resulting recommendations. This dialogue involved 150 managers during a two-month period. Following that dialogue, a consensus over most of the recommendations set the platform for its adoption by senior management. Consequently, a "change package" of strategic and operative policy resolutions in seven major areas has been formulated and published internally as the foundation for working plans for the up coming years (Figure 5).

Figure 5: *Comprehensive policy to promote equity: seven major areas of an action plan.*



The foundation for these actions was the decision taken by MHS that equity promotion will be adopted as a major strategic objective. It means a long-term commitment, involving the allocation of special resources, in order to secure all our members' right to optimal health. It has also been decided that equity would be viewed as a filter through which every policy decision will be screened to ensure that any decision taken by the organization promotes equity, or at least does not increase disparities.

The Action Plan Components that MHS has Adopted

On-going Assessment of Equality

MHS will invest efforts to develop methodology and tools to evaluate health care services equality in four dimensions and the intra relationships between them: A) inputs (infrastructures and human resources) in care provision; B) special populations needs; C) utilization of services by different population groups: poor populations, ethnic minorities, women, children, disabled, etc.; and D) health outcomes.

Cultural Adaptation of Services

MHS will adjust its services to suit its members' ethnic, social, and cultural needs by: A) Recruiting caregivers and managers representing populations at risk for disparities in order to increase the ethnic diversity of its the staff; B) Training health professionals in cultural competency - it has been decided that within 4 years all MHS staff will be trained in cultural competency; and C) Providing professional interpreting services and translated information.

Adoption of Community Orientation in Primary Care

Reduction of disparities will focus on integrating a community-based approach into primary care in order to meet the needs of populations at risk by: A) Working with non-health sectors in the community, mainly education and welfare; B) Developing partnerships with community leaders and third sector organizations; B) empowering the leadership of ethnically diverse caregivers and managers to represent the needs of population at risk at decision-making levels.

Resource Allocation to Social Peripheries

MHS has decided to target resources to "social peripheries" beginning in 2010. Social peripheries are defined by the following parameters: their distance from economic & political centers of power, low access to healthcare services, heavy burdens of disease, low socioeconomic position, and little or no social cohesiveness. The concept of "social periphery" has been powerfully integrated into the MHS policy-making process. The concept originated among civil society organizations, and allows us to approach weak communities, in each of our 5 regions, according to their socio-economic or cultural characteristics, and not simply according to geographic location.

Improved Accessibility of Services in Geographically Peripheral Areas

MHS will improve accessibility by A) video-conferencing between experts and remote clinics, where the GP and patient will attend an on-line virtual consultation; B) mobile diagnostic facilities such as ultra-sound devices; and C) the creation of incentives to encourage specialists to provide service in peripheral areas.

Reducing Economic Barriers to Optimal Healthcare

MHS will ensure that populations requiring support are able to take advantage of their healthcare rights; together with the support of the Ministry of Health, MHS will try to reduce co-payments for targeted patients, such as those suffering from chronic illness and defined as poor or disabled.

Recognition and Reward of Reductions in Disparities over Time

Quality measurement and rewards have proved to be a powerful engine for change and can be used to incentives the reduction of disparities. We are now working on an index that will assess reductions in disparities (an equity indicator) for the purpose of recognizing and rewarding the organization's units for their reduction of disparities over time.

Summary

The first equality report produced by MHS was a significant foundation for the policy making and decisions made by the organization. It was important as a first step in exposing the information about existing disparities and populations at risk for disparities in health provisions and outcomes. MHS has taken major steps to reduce these disparities, but a nation-wide effort is required. The Israeli government through the Ministry of Health, with the four Israeli HMOs, academic experts, and social organizations, are urged to join efforts in establishing nation-wide policy to reduce inequalities.

However, MHS decided not to wait and has initiated major activities to promote the fairness in health.

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Health Inequity in Israel: Past, Present, and Future

Leon Epstein

Introduction

Differences in health status that are considered to be unnecessary and avoidable can be considered to constitute Health Inequity and, therefore, by definition a society should attempt to prevent them or reduce their extent if they already exist (Whitehead, 1990). Health inequity has been found in all countries where it has been studied and Israel is no exception. However, the National Health Insurance Law (NHIL) enacted in 1994 defined clearly in its first paragraph that the health care framework should aim to reduce this inequity to a minimum. It stated that "National Health Insurance according to this Law is based on the principles of justice, equality and solidarity ..." This paper will review the previous situation, the present picture, and what needs to be done in order to improve in the future.

Health Inequity in Israel up to the Present

Data on health inequity have shown that it is reflected in many measures of health status including life expectancy, infant and general mortality, morbidity and disability, accidents, health behavior, and access to quality health services. These exist by many of the characteristics of Israel's heterogeneous population (gender, ethnicity, religion and degree of religiosity, education, employment status, income, age, and geographic area of residence) (Epstein & Horev, 2007). It is pertinent to enumerate some measures of health inequity and especially to highlight a widening of selected measures.

Life expectancy

This is considered to be a valid overall measure of the health status of a population and its health services. It has improved in Israel over the years. However, this improvement hides important differences. There is a differential by region of residence with those who live in the north and south of the country having a life expectancy 3-5 years less than those that live in the center of the country (Israel Central Bureau of Statistics, 2006). In addition, there is a consistent difference between the Arab and Jewish populations over the years that is widening. Whereas in 1996 Arab men had a life expectancy 1.5 years less than their Jewish counterparts, in 2006 this difference grew 2-fold to 4.6 years. While this difference comes about by comparing two individual years, the differential is almost a factor of two when comparing five-year periods. The findings were similar, if smaller, in women (Israel Central Bureau of Statistics, 2007).

Infant mortality

This is likewise considered to reflect population health status. Similar to life expectancy there has been considerable improvement over the past 60 years. However, the Arab/Jewish differential has remained; in the last decade it has risen more than 2-fold (MOH, 2005). In addition, it should be noted that there is a significant and widening difference by educational level of the mother at the time of the birth. In 1993-96 there was a 3.5-fold difference between babies born to women with less than five years of formal education compared to those with an academic education. This rose to a 4.6-fold difference in 2000-2002 (MOH, 2001, 2005). This finding is of special relevance to the health care professional. At the time of a woman's visit to a health care service during pregnancy or with her baby during its first year of life, it is too late to change her formal educational status. What should and can be done in order to reduce the effects of this substantial social risk?

Morbidity

The Quality Indicators Program in Community Medicine in Israel (MOH, 2008) has provided an important insight into health inequity related to morbidity. As an example, it has been shown that there is a difference in prevalence of diabetes by income level at all ages and that in the total adult population over age 25 it reaches a factor of 4.5 when comparing those with very low income to the remainder of the population. In addition, the level of control of diabetes (HbA1C levels) is worse in the low income group - in the most recent report this differential has been slightly reduced. It should be stated that there was no evidence of health inequity in all the indicators measured, but the data on diabetes mellitus are of special relevance because of the high prevalence and its significant complications. There is, however, an additional lesson to be learned in relation to diabetes. Before the creation of the State of Israel and shortly thereafter there was significant migration from Yemen. It was found that the longer the immigrants were in Israel the greater the prevalence of diabetes and with it the complication of coronary heart disease. This was hypothesized to be due primarily due to a substantial change in diet (Cohen, 1961; Toor, Katchalsky, Agmon, & Allalouf, 1957). Since the 1980s there have been two waves of immigration from Ethiopia. History has repeated itself and the prevalence of diabetes, almost non-existent at migration, has risen to significantly high levels (Jaffe, Guttman, & Schuster, 2008.

Disability

A recent Ministry of Health report has shown that there are differences in the prevalence of disability by gender, age, ethnicity, religion, level of education, and socio-economic status of dwelling area (Shemesh & Levy, 2009).

Health Behavior

Studies have shown socio-economic and cultural differences related both to the risk to health as regards smoking (MOH, 2004), dietary intake (MOH, 2003), and physical activity (Shemesh & Rasooli, 2003), as well as in relation to the response to performance of early diagnostic procedures (MOH, 2008; G. Rennert, unpublished data).

The Causes of Health Inequity

From the above short review, there is considerable evidence of health inequity in Israel up to the present and that in important measures the gap is even widening. It is, however, important to move to an understanding of the causes for this and on this basis to consider the potential and process for reduction of the disparities.

The explanatory factors have been reviewed in detail in various publications (Epstein & Horev, 2007; Epstein, Goldwag, Isma'il, Greenstein, & Rosen, 2006; IMA, 2008) and will be summarized here.

1. As indicated in the World Health Organization Commission on Social Determinants of Health Report in August 2008 (WHO, 2008), the major factor in the etiology of health inequity lies in the socio-economic differential within and between countries. This exists in Israel to a marked extent as is also evidenced in the recent OECD Report (OECD, 2009).

2. There are, however, specific economic barriers to be considered:

   - Co-payment for health services recommended by the patient's physician has been shown to be an important barrier to the receipt of care. Biannual studies by the Brookdale Institute have revealed that almost 30% of the families in the lowest income quintile were unable to pay for drugs or for treatment or consultation at least once in the past year (Gross, Brammli-Greenberg, & Waitzberg, 2009). The Israel Medical Association annual study of health care has shown that this has been exacerbated especially in the elderly between 2007 and 2008 (Degani & Degani, 2009). The possible relevance of the global economic recession cannot be underestimated.

   - Since the enactment of the NHIL there has been a significant change in the source of funding for health care in Israel. The public share has fallen from 66.5% to 54.6%, while the private share (not including the health tax) has risen from 31.4% to 43% (Bennun, 2009). This is in contrast to the OECD where the private outlay has consistently fallen. In addition, it is interesting to note that over the period 1997-2005 the per capita outlay rose by NIS410. However, this was balanced by a decrease of NIS521 in public outlay per capita and a rise of NIS931 for private expenditure (Bennun, 2009). It can therefore be stated that the financial burden of health care funding has fallen more and more on the public in a society with a widening economic differential in income.

3. Health Care infrastructure: Access to quality health care is an obvious necessity in a modern society. However, where health inequity is extensive and growing and related to socio-economic indicators such as area of dwelling and income, among others, the question does arise as to the relevance of access to services. In Israel there is a constant difference in availability of general hospital beds, dialysis stations, pediatric intensive care beds, and beds for the chronically ill and the disabled (rehabilitation) (Epstein & Horev, 2007; Shemesh & Levy, 2009). These disparities are between the north and south of the country compared to the center. It should be noted that there is a similar differential in income and in major health measures. While extra hospital beds will possibly not correct health inequity, their lack needs to be corrected.

On this background of the existence of extensive health inequity and its possible causes, it is of value to review highlights of past activities, recent actions, and what is required in the coming years.

The Past – Until 2000

a. The highlight was certainly the enactment of the NHIL; however, while it provided more comprehensive health insurance, especially to minority groups, it did not have the expected impact on health inequity.

b. Extensive routine data collection has been developed on a national level by official institutions – Central Bureau of Statistics, Ministry of Health, and Health Funds – that later provided the necessary data for assessing the existence and extent of health inequity.

c. Research projects, usually on selected disease entities, were performed largely in academic institutions, but the findings had little impact on overall policy and action.

d. Where data became available, isolated intervention projects were undertaken but were often limited in time, depended on the continued involvement of the person initiating the action, and were not taken to the national level.

The Present 2000-2009

a. Policy-related research was performed that included clear recommendations as to action that was needed to reduce health inequity (Epstein, et al., 2006; Epstein & Horev, 2007).

b. Two of the major Health Funds took strategic decisions to move both to defined policy and planned action to reduce the health inequity in their insured populations (Balicer et al., 2009; Wilf-Miron et al., 2009).

c. The Israel Medical Association defined health inequity as a priority subject and developed policy and action recommendations that were circulated to all physicians in the country and submitted to the Ministry of Health (Israel Medical Association, 2008).

d. The Quality indicators for Community Health (MOH, 2008) have been shown to have an impact on the functioning of the Health Funds and are potentially a very important tool in the monitoring and evaluation of health inequity and planned interventions.

e. The Ministry of Health has included health disparities in its action objectives and has designated a framework that will be responsible for these activities.

The Future

Notwithstanding the accumulation of the evidence on health inequity and clear recommendations regarding possible action, there is as yet no National Policy, at the Governmental level, regarding Health Inequity in Israel. Constituents of such policy would need to include:

- The clear recognition of the existence of the issue and the need for planned action at the individual, family, health care system, and overall national levels.
- Recognizing that Health Inequity will not be substantially reduced by Health Care system action alone; it is clear that intersectoral planning, in line with the recommendations of the WHO Commission, is a prerequisite for any successful attempt to reduce the health disparities.

- Further to the above, it is incumbent on the Health Care System, and the Ministry of Health as the prime initiator, to clearly define its role regarding these issues. In principle, this can be defined as follows:
  - To prevent the health effects of socio-economic and cultural inequality and inequity – especially by health promotion and disease prevention activities (primary prevention). For example, as previously indicated, maternal education has been identified as a major risk factor for infant mortality. The HCS must determine what action it needs to take in order to prevent the health effect (infant mortality) of the social risk (maternal education).
  - To identify, treat, and reduce existing Health Inequity by early diagnosis of disease, quality management of chronic disease, e.g., diabetes, and rehabilitation (secondary and tertiary prevention). Stress must be placed on the fact that health care cannot be considered to be of high quality if health inequity exists (Institute of Medicine, 2001). This is clearly of major relevance to the health care professional.
- Economic and infrastructure barriers in the planning, delivery, and access to equitable health care have been referred to. Change in them will require extensive involvement of the Ministries of Finance and Health.
- The principles of Culturally Appropriate Health Care have been defined in Israel (Epstein, 2008). These now need to be translated into an integral part of the National Policy for reduction in Health Inequity.

Summary

Available data indicate extensive health inequity in Israel. While it is not feasible to expect the complete elimination of health inequity, it can certainly be reduced both by action within the Health Care System in relation to primary prevention, by appropriate clinical management where the disparity already exists, and by intersectoral action on the social determinants, especially aimed at the economic, educational, and cultural barriers.

It will require both political and professional will to recognize the problem and accept responsibility for action.

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Tackling the Inverse Care Law in the UK

Rosalind Raine

> “The Availability of good medical care tends to vary inversely with the need for it” (Tudor Hart, 1971)

Introduction

This essay reflects my personal perspective and thus focuses on the work undertaken by my research team to address the following questions.

Does the Availability of Health Care Vary by Socioeconomic Circumstances in the UK National Health Service (NHS)?

The NHS is a tax-funded system based on the premise of universal access to health care for all, solely on the basis of clinical need, and undistorted by social or economic factors, such as geographical location or ability to pay. Yet observers have long recognized the presence of the so-called “inverse care law” operating in the NHS (Tudor Hart, 1971). This term was first coined in 1971 by Dr. Julian Tudor Hart, a general practitioner who worked in socially deprived mining communities in the Welsh valleys. His observation that “the availability of good medical care tends to vary inversely with the need for it in the population served” was largely based on his personal experiences rather than on empirical research. However, the wealth of confirmatory data that has been published since 1971 led the chief medical officer for England to observe recently that “Healthcare in the NHS is to some extent inequitable at present: the preference of clinicians, the socioeconomic status and empowerment of patients, and decisions regarding local resource allocation may influence clinical practice as much as the actual health needs of patients, the behavior of any pathological process or the scientific evidence base.” (Department of Health, 2006).

Inequalities have been demonstrated at each stage in the health care pathway: in participation in population-based screening programs in the community (Weller et al., 2007), in the management of mental health problems in primary care (Raine et al., 2000), and in access to diagnostic and therapeutic procedures within secondary care (Downing, Prakash, Gilthorpe, Mikeljevic, & Forman, 2007; Hippisley Cox & Pringle, 2000). Most of the research undertaken in this area examines social variations in health care use for a defined intervention (or package of interventions) at one point in the management pathway. When inequalities are uncovered it is therefore not possible to conclude whether the disparity occurs at the level of the intervention under consideration, as a consequence of inequalities in the provision of preceding interventions, or in direct (and appropriate) response to the results of previous investigations. For example, my review of gender bias in use of cardiac care found that high quality prospective studies reported gender differences in favor of men in the use of angiography (Raine, 2000). However, there was consistent evidence of no gender difference in those patients in whom the results of previous investigations had been taken into account. Thus, the entire management pathway needs to be examined to establish the reasons for the differences found. In the case of angiography, it is likely that the gender inequalities identified were not inequitable in that they were fair and made on the basis of clinical need (identified by the earlier investigation).

Identification of the “rate limiting step” driving health care inequalities is of key relevance to policy makers when planning the reorganization of care to improve health and reduce inequalities. During the mid-1990s it became increasingly apparent that cancer survival in England was lower than the European average (Berrino et al., 2007; Janssen-Heijnen et al., 1998; Sant et al., 2003). Socioeconomic inequalities in survival also widened during this decade for colorectal cancer and did not improve for lung and breast cancer (Verdecchia et al., 2007). In response, the NHS Cancer Plan (Department of Health, 2000) brought substantial financial investment to cancer services, with particular focus on service reconfiguration in secondary and tertiary care. However, our evaluation of the Plan found mixed evidence for improvements over time in terms of mode of access to these specialist services. Nearly one-third of colorectal cancer patients were admitted as emergencies and this proportion did not improve over time. Over half of lung cancer patients were admitted as emergencies and this proportion increased over time. Only for breast cancer was the picture better, with a downward trend in the proportion of patients who were admitted as emergencies between 1999 and 2006.

However for all these cancers, patients from deprived areas, older people and women continue to be more likely to be admitted as emergencies (Table 1). For example, the adjusted odds ratio (OR) for emergency admission for breast cancer patients in the least- compared with most-deprived quintile of deprivation was 0.63 (95% confidence interval 0.60–0.66) and the adjusted odds ratio for lung cancer patients aged 80–89 compared with 50–59 year olds was 3.13 (2.93–3.34). These findings highlight the need to shift attention from the provision of high quality specialist care towards improvements much earlier in the patient pathway to ensure timely presentation and early referral, if we are to improve outcomes overall and reduce inequalities.

Table 1: *Effect of social factors and admission period on emergency admission for patients with colorectal cancer (1 April 1999 to 31 March 2006).*

Variable	Total	Odds ratio (95%CI)	p value
Men	102,772	1	
Women	84,205	1.15 (1.12–1.17)	<0.001
Index of multiple deprivation (fifths)			
1 (most deprived)	34,404	1	
2	36,470	0.83 (0.80–0.86)	
3	39,309	0.75 (0.72–0.77)	<0.001
4	39,753	0.68 (0.65–0.70)	
5 (least deprived)	37,041	0.66 (0.64–0.68)	
Age group (years)			
50–59	25,002	1	
60–69	47,149	1.05 (0.98–1.11)	
70–79	67,625	1.41 (1.33–1.49)	<0.001
80–89	41,299	2.53 (2.37–2.69)	
≥90	5,902	5.85 (5.23–6.55)	
Admission period			
Per year	–	1.00 (0.98–1.01)	0.595
Interaction between age group and admission period			
50–59 × period	–	1	
60–69 × period	–	1.00 (0.98–1.01)	
70–79 × period	–	0.98 (0.96–1.00)	0.010
80–89 × period	–	0.98 (0.96–1.00)	
≥90 × period	–	0.99 (0.96–1.02)	

In what Circumstances are Health Care Inequalities Most Likely to Occur?

Systematic reviews of socioeconomic variations in the use of specialist hospital services do not clarify whether inequalities occur once patients are within the secondary sector or at the point of referral to specialist care (Dixon, Le Grand, Henderson, Murray, & Poteliakhoff, 2007). Given general practitioners' (GP) control over access to much of the rest of the NHS and the continued shift in power and resources to primary care, there is a need to better understand factors determining GP referral decisions in order to shed light on the circumstances in which health care inequalities are most likely to occur at this key point of access to further NHS care.

Our approach was to compare social variations in the likelihood of referral for symptoms that varied with respect to the presence of national referral guidance and their potential to be life threatening (McBride, Hardoon, Walters, Gilmore, & Raine (2010). We used The Health Improvement Network (THIN), a widely used primary care database, to analyze individual patient data from nearly 130,000 patients from 326 general practices across the United Kingdom. We hypothesized that socio-demographic variations in referral would be less likely for potentially life threatening conditions and with national guidance on referral (post-menopausal bleeding [PMB] and dyspepsia in people over 55 years-of-age; in these cases it is necessary to exclude a cancer diagnosis) and more likely for symptoms where there was clinical uncertainty regarding the decision to refer (e.g., hip pain and dyspepsia in people under 55 years-of-age).

We found that 61.4% of PMB, 17% of hip pain, and 14% of dyspepsia patients were referred between 2001 and 2007. For the three conditions examined, older patients were less likely to be referred, after adjusting for co-morbidity. Thus, for PMB, the likelihood of referral declined with increasing age, the adjusted odds ratio (OR) for ≥ 85 year olds compared with 55-64 year olds was 0.39 (95% confidence interval [CI] 0.31-0.49). Hip pain patients aged 85 years and above were also less likely to be referred compared with 55-64 year olds (adjusted OR 0.68, 95%CI 0.57-0.81). We also found that women were less likely than men to be referred for hip pain (hazard ratio, HR 0.90, 95%CI 0.84-0.96). More deprived patients with hip pain and dyspepsia (if under 55 years old) were less likely to be referred. Adjusted HRs for those in the most deprived quintile compared to the least deprived were 0.72 (95%CI 0.62-0.82) and 0.76 (95%CI 0.68-0.85), respectively. There was no socio-economic gradient in referral for PMB.

Thus, we demonstrated striking inequalities by socioeconomic circumstances, age, and gender in the likelihood of referral for those conditions (hip pain and dyspepsia in younger people) where clinical judgment cannot be informed by guidelines or driven by the need to exclude a cancer diagnosis. These findings are important given the widespread prevalence of non-specific symptoms for which explicit referral guidance does not exist, but which could, none the less, be indicative of serious underlying pathology (e.g., lung, colorectal, and ovarian cancers).

Do Such Inequalities Matter?

In order to address this question we must distinguish between the related concepts of equity and equality. Equity is about fairness and justice, and implies that everyone should have an equal opportunity to attain their full potential for health or for health care. Recent work in moral and political philosophy contends that equity in health care is a basic need of a fair society and a legitimate expectation of all who are subject to its rules and who contribute to its wellbeing as workers, taxpayers, and community members (Raine & McIvor, 2006). Within the NHS, health care inequity matters because it undermines the capacity of the NHS to remain true to its core values.

The notion of equity encompasses equality. Equality is about comparisons between the level of health, or ability to obtain health care, of individuals and communities. Thus, inequalities can be justified if they occur as a consequence of, for example, social variations in treatment effectiveness.

We examined this in the case of secondary drug prevention for patients who survived a stroke (Raine et al., 2009). We defined secondary prevention as the prevention of recurrences or exacerbations of a disease that has already been diagnosed. Once again, we used THIN to undertake a national cohort study of 12,830 patients aged 50 years and above from 113 general practices who experienced a stroke between 1995 and 2005 and who survived the first 30 days after their stroke.

We found low rates of receipt of secondary prevention: only 25.6% of men and 20.8% of women received secondary prevention. Receipt of secondary prevention did not vary by socio-economic circumstances or by gender. However, older patients were substantially less likely to receive treatment. The adjusted OR for 80-89 year olds compared with 50-59 year olds was 0.53 (95%CI 0.41-0.69). This was due to older people being less likely to receive lipid lowering drugs (e.g., adjusted OR for 80-89 year olds was 0.44 [95%CI 0.33-0.59] compared with 50-59 year olds). Secondary prevention was associated with a 50% reduction in mortality risk (adjusted Hazard Ratio [HR] 0.50, 95%CI 0.42-59). On average, patients on treatment had 5.7% mortality within the first year compared to 11.1% for patients not receiving treatment. These values changed little by gender and across socio-economic groups. Younger patients, because of their lower mortality rate, exhibited little absolute difference in mortality (2% of treated compared to 3.9% of untreated patients amongst 50-59 year olds), whereas older patients exhibited a larger absolute difference (10.5% of treated compared to 20% of untreated patients amongst 80-89 year olds).

Thus, we found evidence of an association of reduced treatment with older age, with the odds of receiving secondary prevention for 80-89 year olds only half that for 50-59 year olds. This was entirely due to older people being less likely to receive lipid lowering drugs (more so in the late 1990s than in the early 2000s). This variation in treatment is important because the receipt of secondary drug prevention was associated with a 50% reduction in the hazard of dying during the first year for those patients who survived the first 30 days after their stroke. This reduction in hazard had different implications for different age groups due to the underlying increased rates of mortality for older people. Crucially, there was little evidence that the effect of treatment differed between the social groups examined. Therefore under-treatment of older people cannot be justified, unless it is explained by informed patient choice. If patient preferences explain some of the differences observed, then it is important to unravel their origin. This is a theme that I discuss later in this essay.

Will Policies to Improve Access to Health Care Reduce Health Inequalities?

Structural actions (i.e., fiscal and environmental policies) that prompt social and economic change are essential determinants of health and health inequalities (Marmot et al., 2010). Meanwhile the NHS is currently largely responsible for public health policies that emphasize the role of individual behaviors. For example, it provides smoking cessation services and exercise referral schemes to encourage people to adopt healthy behaviors. The NHS is also responsible for ensuring equitable access to effective health care interventions.

The contribution of medical care to population health has been a topic of scientific debate for many years. McKeown's work in this area sparked considerable controversy, but there is agreement with his claim that clinical interventions played little role in the decline of mortality prior to the mid-twentieth century (Colgrove, 2002). Major advances in medical technology during the twentieth century stimulated a re-examination of the role of health care on population health. International studies have focused on coronary heart disease (CHD). They suggest that 50–75% of the decrease in cardiac deaths can be attributed to population level improvements in the major risk factors, particularly smoking, but also cholesterol and blood pressure (Capewell, Beaglehole, Seddon, & McMurray, 2000; Capewell, Morrison, & McMurray, 1999; Hunink et al., 1997; Unal, Critchley, & Capewell, 2004), whilst the remaining 25–50% of the decrease in mortality can be attributed to medical intervention. Amongst patients with established CHD, nearly 78% of prevented or postponed deaths are attributable to medical or surgical intervention (Unal, Critchley, & Capewell, 2005).

However, such research does not address the question of whether the contribution of health care to improved health outcomes is similar across population sub-groups. This is a particularly relevant issue given the poorer risk factor profile of socially disadvantaged people in combination with evidence of socio-demographic variations in entry to and subsequent uptake of care. Thus, to estimate the potential of health services to reduce health inequalities, we need to determine variations and estimate future trends in behavioral risk factors, health care use, and outcomes, all by socioeconomic circumstances. We are currently working on a project to do just this. However, we are aware that clearly disentangling the contributions of specific population-based strategies (such as taxation policies, advertising legislation, or public health initiatives) on behavioral risk factors and subsequent health inequalities remains an elusive goal (CSDH, 2008). In part this is because whilst the use (and effects) of defined medical and surgical treatments can be individually quantified, social policies and public health initiatives often occur coincidentally, may have variable levels of absorption, and lack standard measures of implementation or uptake. Furthermore, individual level characteristics such as functional differences and cultural beliefs are integrally entwined with the social and environmental context in which people live and can facilitate or constrain behavior change (Kreiger, 2008). Whilst we hope to obtain a handle on the relative contribution of medical and surgical therapies to health inequalities, the "causes of the causes" with respect to the precise drivers of population risk factors will require further research. The importance of this work is that it is needed to inform debates about how resources should be distributed between public health and health care interventions, and the extent to which policies should focus on structural drivers as opposed to the role of the individual to reduce inequalities.

What are the Best Ways to Tackle the Inverse Care Law?

This leads me to the on-going debates about the best way to tackle the inverse care law. I have begun to touch upon the first topic, that of the primacy of state intervention versus individual freedom. Other themes that I will address are: the current U.K. policy emphasis on behavior change; and whether we should address the gap or the gradient in health care inequalities.

State Intervention versus Individual Freedom

In 2004 New Labour published its White Paper on Public Health, *Choosing health: making healthy choices easier* (Department of Health, 2004). This signaled a policy shift away from societal and towards individual responsibility. *Choosing health* set out a clear statement of the values on which policy was to be based – that of "informed choice". The

Department of Health appeared to embrace the arguments set out by John Stuart Mill in his essay *On liberty*, in which he argued that the only justification for the state to constrain the actions of an individual are when an individual's actions risk harming others (Mill, 1982). This would explain the Government's willingness in 2007 to introduce legislation to make enclosed public and work places smoke-free. Yet it is not as simple as Mill suggested, because people's choices are constrained. These constraints can be environmental, involving structural, organizational, and financial barriers, as well as individual, such as psychological and informational barriers (McKee & Raine, 2005). The Secretary of State at the time acknowledged this when he borrowed from Marx and told us that the driving force behind the White Paper was the recognition that "men and women make their own choices but do not do so in circumstances of their own choosing". The muddled philosophical thinking underlying Choosing health exposed a tension which remains unresolved in English health policy to this day. On the one hand, the Government wishes to distance itself from accusations of being a nanny state and to be seen to respond to people's desire to make their own "informed" decisions - even if that involves choosing unhealthy options. On the other hand, it recognizes the power of circumstance on people's lives and the speed at which state intervention can deliver improvements in the public's health.

Behavior Change: Unpacking Patient Preference

I would like to delve deeper into this notion of "informed" decision making and begin to unravel the origin of patient preferences. We know that there are gender, age, ethnic, and socioeconomic differences in patient preferences for defined health care interventions (Katz, 2001; Manderbacka, 2005). These may be secondary to practical barriers, such as a reluctance of those with caregiver responsibilities or who are self-employed, to take time out to undergo a surgical procedure with its associated rehabilitation time (Karlsen, Daltroy, Liang, Eaton, & Katz, 1997). However, other factors should also be considered. These include systematic socio-demographic differences in expectations for good health and in perceptions of the risk and benefits of specific interventions. Such perceptions are likely to be defined, in part as a result of interactions with doctors. It has long been recognized that such interactions are socially patterned (Willens, De Maesschalck, Deveugele, Derese, & De

Maeseneer, 2005). For example, age-related variations in preferences for total hip replacement may be justified in terms of older people being less willing to undergo procedures due to concerns about good outcomes or adverse consequences (Hawker et al., 2002). However, concepts of risk may be colored by beliefs about "good innings" or "normal" ageing (Williams, 1997). Thus, mortality and function after hip surgery are worse for older compared with younger patients, but the absolute differences are small and, on average, older people can still expect an improvement in quality of life (Santaguida et al., 2008). The way in which this information is framed is likely to influence the decision made.

Furthermore, even in the presence of research evidence to the contrary, if clinical experience and beliefs are not consistent with that evidence, then the clinicians' experiences and beliefs (e.g., about certain "types" of patients) seem to take precedence in their decisions about appropriate care (Raine et al., 2004). All these data point to the need to acknowledge the impact of health care professionals' beliefs on their consulting behavior. Yet Department of Health policies on behavior change focus on campaigns and activities to encourage patients to shift their behavior whilst there is scant recognition of the need to address health care professionals' behavior.

Gap or Gradient?

There is a real dilemma about whether to focus on the inequalities gap or gradient. The gap refers to the difference between the worst-off in society and the better (or best)-off, whereas the gradient refers to the stepwise relationship between socioeconomic group and health. This graded relationship, whereby more socio-economically advantaged individuals have better health and better access to health care, is well known (Graham, 2004). The costs of inequalities are therefore borne not only by those at the bottom of the socioeconomic hierarchy but at every level. Policies that target the most disadvantaged subgroups only, or which aim to narrow the gap between the most and least disadvantaged, under-estimate the pervasive effect across the socioeconomic hierarchy and exclude those in need in the intermediate socioeconomic groups. Such arguments, which augur in favor of taking a universal approach to addressing inequalities, need to be tempered against the findings of Cesar Victora (Victora, Vaughan, Barros, Silva, & Tomasi, 2000). He proposed the "inverse equity hypothesis" to explain the unintended adverse consequence of universal establishment of interventions that he uncovered when evaluating the introduction of child public health programs in Brazil. He demonstrated that "health inequalities, measured in terms of relative differences in outcome rates, initially tend to increase as advantaged populations are the first to benefit from the new intervention; but eventually inequalities will tend to decrease as rates of advantaged groups approach a 'minimum achievable level' beyond which further improvements are difficult or impossible." It is not yet clear whether this hypothesis also applies to universal public health programs in developed countries, but there is some indication that it may not be inevitable.

We recently examined the extent to which there is equitable access to two public health programs in England: Exercise referral schemes and the English National Chlamydia Screening Programme. Exercise referral schemes involve GP referral of sedentary patients with existing health problems to a program of subsidized exercise at a local leisure centre. Our cross-sectional analysis of patients referred by 317 general practices between 2004 and 2006 found that general practices within areas of deprivation were more likely to refer patients to exercise referral schemes than practices in more advantaged areas (Sowden, Breeze, Barber, & Raine, 2008). Once referred, patients living in deprived areas were as likely to take up (adjusted OR, least versus most deprived quintile 1.05, 95%CI 0.83-1.33) and to complete the scheme (adjusted OR 1.23, 95%CI 0.84-1.79) as those living in more advantaged locations. Furthermore, secondary analysis of 550,000 screening records from the English National Chlamydia Screening Programme found that screening provision and coverage were highest in more socioeconomically deprived areas where the risk of chlamydia was also greatest (Sheringham et al., 2010). These findings are encouraging with respect to the possible lack of generalizability of the inverse equity hypothesis to the NHS setting. It is possible that the results can be explained, at least in part, by the fact that for both initiatives, there have been drives to ensure that provision is concentrated in deprived areas. However, the results must be treated with caution: in both cases overall participation is low and long-term effectiveness and cost effectiveness of these schemes has yet to be established.

This focus on addressing the gradient may simply not be feasible when tackling complex, multi-factorial, and enduring problems. In these cases, it might only be feasible to attend to the inequalities gap. An example of such an approach is embodied in the English Family Nurse Partnership Programme (FNP, 2010). This provides intensive support to first-time mothers who are under 20 years old. Many have mental health, drug, and alcohol problems and may also be leaving statutory care services. It costs over £30M and is being introduced across England. The English program is currently being evaluated, but it is based upon the rigorously evaluated and effective U.S. Nurse Family Partnership (NFP; Olds, 2002). Over 30 years, research based on randomized controlled trials of the program in several U.S. states has shown that it improves prenatal health and can reduce childhood accidents, abuse, and neglect. The mothers involved have fewer subsequent pregnancies and are more likely to work. The research suggests the benefits are long term. By the age of 15, children who were part of the NFP in the United States are less likely to be abused or neglected, less likely to be arrested, and less likely to be sentenced to prison.

Back in England, there is a risk that these potentially impressive benefits for the few could have detrimental implications for the sizable number of mothers who need intensive support but who are over 20 years old and so are ineligible for the Family Nurse Partnership Programme. Evidence of other targeted community interventions suggests that this approach could result in the most skilled staff drifting from generic health visiting to the new specialist service (Craig, 2003). This could result in women in need receiving both less care and less high quality care.

What is the Best Way Forward?

The conclusions I draw from the research I have described include the need to consider the following policies to achieve health care equity:

First, for prioritized interventions of proven effectiveness and cost effectiveness, there should be universal provision where these are discrete and simple interventions. Performance targets should be set by socioeconomic group to promote strategies to provide appropriate services on the basis of clinical need, and undistorted by social factors, and to allow monitoring of uptake by socioeconomic group. Intensive evidence-based interventions are required for complex health needs. But we must avoid the drawback that may affect families in need who fall outside the remit of the English Family Nurse Partnership Programme. Where a public health or health care problem has been prioritized for intervention, we can draw on the Government's strategy of "progressive universalism", defined as "raising standards for all but providing more for those who need it" (Prescott, 2002). For this strategy to work and to ensure that people in need are not neglected, matching of explicitly identified levels of needs to defined packages of care is required so that it can be demonstrated that equal and appropriate provision occurs at every level of need. Thus services may be unequal but they will not be unfair.

Second, uptake of NHS services should be monitored by socioeconomic group. Despite the acknowledged socioeconomic variations in health care use, this is not current routine practice. Moreover, health inequalities targets relate to subsections of the national population and do not capture the social gradient in health. I suggest that it should be a commissioning requirement for routine data to be collected by socioeconomic group at each significant point in the patient pathway. This can easily be done by mapping routinely collected post code data to a publicly available and widely used area-based measure of socioeconomic circumstances, such as the Index of Multiple Deprivation (Noble, McLennan, Wilkinson, Withworth, & Barnes, 2008). This will enable the identification of the specific point in the pathway where inequalities originate, and the monitoring of inequalities in access, use, and outcome by socio-economic group.

Finally, we need to design and evaluate interventions that aim to reduce socioeconomic inequalities in uptake of health care interventions and do not compromise uptake in any socio-economic group. These interventions should address both patient and health care professionals' behaviors and should, ideally, be evaluated using an experimental, rather than observational research design.

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Health Rights Information from the Perspective of Ethiopian Immigrants: Issues, Barriers, and Policy Recommendations

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Introduction

Attaining equitable and appropriate healthcare can largely depend on the extent to which people know what their health rights are and how to realize these rights. For example, they may need to know what services they are entitled to receive, what their choices can be, and whether they can contest a particular administrative decision. Communicating health rights information to Ethiopian immigrant populations poses several challenges that go beyond those of communicating about health rights information to the general population: Ethiopian immigrants face various social, cultural, acculturation, and language barriers in the healthcare system. This chapter presents findings from the perspective of Ethiopian immigrants regarding which factors they perceive serve as barriers to members of the Ethiopian community to attain health rights and their conceptions regarding communicating about health rights by using narrative approaches. The chapter concludes with a series of policy recommendations for developing and communicating health rights information to Ethiopian immigrant populations in Israel.

Challenges and Stipulations Regarding Public Knowledge about Health Rights

One of the guiding principles of the Israeli National Health Insurance Law is that all residents will have the ability to realize their health rights. In order to fulfill this stipulation an important condition is that all residents, regardless of language, culture, or economic means, will be aware of these rights, comprehend them, and understand their implications. The National

Health Insurance Law designated several organizations in the health care system to disseminate health rights information, among them the National Health Council and the healthcare funds, which receive public funds and provide healthcare services (Shalev, 2003). The Israeli National Health Insurance Law came into effect in January 1995 (Shalev & Chinitz, 1997). Until then, people were insured mainly through several non-government organizations. The Law determined that all residents will receive services through one of four public healthcare provider organizations. The rights accorded by the Law include the right to choose one's healthcare provider, to switch from one healthcare organization to another, and to lodge complaints. In addition, it defined a uniform basket of a wide range of services and medications, which the health funds are obliged to provide members according to specified health conditions.

Research findings of a comprehensive study on health rights information in the general population in Israel indicate that across various sociodemographics, Israeli residents have a limited knowledge of health rights. One of the study's major conclusions was that information about health rights needs to be disseminated in a way that they are perceived both as personally relevant and as something people believe they can attain. This is especially important for residents from low-income and minority populations, among whom the gap between their needs and attaining their health rights may be relatively large and is influenced by their conceptions of limited ability to attain them (Shalev, Kaplan, & Guttman, 2006). In addition, researchers contend that whereas one of the primary goals of Israel's law was to attain equality, more than a decade after its legislation, the present health system does not make this possible; its universal legislation does not address special needs of populations such as Bedouin and Ethiopian communities (Schwartz-Ilan, Shvarts, Gross, & Goldberg, 2005). By implication, communicating health rights information to Ethiopian immigrants in Israel poses challenges related to attaining equity associated with institutional barriers as well as those associated with cultural and language barriers, acculturation, low literacy, limited knowledge of Hebrew, and economic and social marginalization.

Ethiopian Immigrants in Israel

Currently it is estimated that there are over 120,000 Ethiopian immigrants living in Israel, and a small number of new immigrants continues to arrive and reside temporarily in immigrant absorption centers. Whereas a small number of Ethiopian Jews found ways to immigrate to Israel throughout the years, the main immigration started in the mid-1970s, and the first large wave of immigration took place in 1984. Most immigrants typically made their way by foot in a dangerous journey from their home in Ethiopia to Sudan and were stationed in camps before being flown to Israel. Many families lost close relatives in this journey or while stationed in the transition camps. This wave of immigration, however, had to be discontinued because of political pressure in Sudan. The next wave of immigration took place in 1991, when immigrants who resided in transition camps were airlifted again from Sudan. Thus, the immigration process of the two main waves of immigration to Israel was prolonged and involved various hardships including physical attacks, severe living conditions, illness, and death of relatives. It is estimated that at least 4,000 people died. These circumstances have contributed to stress and a sense of trauma among the Ethiopian immigrants, which remain with many today.

The Ethiopian immigrants in Israel constitute an immigrant population with unique characteristics and needs. Many of the older adults lack formal education (it is estimated that only about a fifth have completed high school and about a fifth had no formal education). Further, when the immigrants came to Israel they had little familiarity with its educational, healthcare, and occupational system, and a large percent (estimated to be nearly half) have a low income or receive public assistance. Most Ethiopian immigrants came from a vastly different social system in terms of family relations, gender roles, and mutual support. A large majority of those over 65 cannot converse in Hebrew, and live in low-income areas with a high concentration of Ethiopian immigrants (King & Netzer, 2003; Offer, 2004). The Ethiopian immigrants also face the challenge to preserve their unique heritage and maintain their sense of dignity; there is a strong sense of discrimination and a feeling that the Israeli society looks down upon them.

Reiff, Zakut, and Weingarten (1999) explain that migration-related stress has affected practically every dimension of the Ethiopian immigrants' life, including family, work, community, housing, nutrition, religious practices and authority, and bureaucracy. Most Ethiopian immigrants upon arrival to Israel have had to adjust to a different type of healthcare system and to learn about and manage Western chronic diseases. These illnesses (such as diabetes) are increasingly prevalent among the immigrant population, although previously they were literally unknown to them in Ethiopia, and it is estimated that certain illnesses have an even higher prevalence among the immigrants than in the general population (Bursztyn & Raz, 1995; Trostler, 1997). The Ethiopian immigrants face difficulties when encountering the healthcare system and when communicating with healthcare professionals in expressing medical symptoms, both because of language gaps and in cultural views of health and illness (Hodes, Teferedgne, & Yodfat, 1996; Myers-Joint-Brookdale Institute, 2001; Nudelman, 1994; Youngmann, Minuchin-Itzigsohn, & Barasch, 1999). Further, there is evidence that the quantity and quality of healthcare services Ethiopian immigrants receive is lower than the quality received by non-Ethiopian patients, in particular fewer early detection and diagnostic tests and visits to medical specialists than those received by non-Ethiopian counterparts (Toledano et al., 2006). In a study that compared healthcare services received by Ethiopian immigrants and a comparison group, the Ethiopian immigrants tended to rank lower than the individuals in the comparison group in their ability to comprehend their doctor's explanations and in their comprehension of the pharmacist's instructions; they also reported a lower frequency of discussions about diabetes with the nurse. The issue of trust also becomes critical in Ethiopian immigrant-health care provider relations when some Ethiopians feel they are discriminated against, not taken seriously, or not understood (Toledano et al., 2006). Also, health care providers report they have difficulties in communicating with Ethiopian immigrants, both because of their limited proficiency of Hebrew and cultural differences.

The Study on Health Rights Information for Ethiopian Immigrants

The findings reported in this chapter on issues associated with health rights from the perspective of Ethiopian immigrants draw on findings from a study we conducted on communicating health rights information for Ethiopian immigrants. A detailed description of the study (funded by the Israel National Institute for Health Policy) and its findings can be found in the research report (Guttman, Aycheh, Gesser-Edelsburg, Bloch, & Avital, 2009). The study had two main objectives: to identify from Ethiopian immigrants' perspective, their particular needs and views regarding health rights, and to develop and test theory-based prototypes as means to communicate health-rights information in a culturally centered way. In this chapter we focus on findings regarding the issues Ethiopian immigrants specified as posing difficulties in attaining health rights, on rights related to health which they felt were particularly relevant to them, and on policy recommendations that emerged from these findings.

The study employed qualitative research methods, which included personal and group interviews with Ethiopian immigrants from different age groups, with different levels of formal education, and from different immigration waves. In addition, interviews were conducted with healthcare and health rights practitioners. Interviews were conducted with 143 participants, of whom 135 were Ethiopian immigrants. Most participants were members of the community, but interviews were also conducted with 31 professionals or paraprofessionals, among them 13 were Ethiopian immigrants. The participants in the study were recruited from various towns: Afula, Ashdod, Bat Yam, Be'er Yaacov, Beit Shemesh, Hadera, Haifa, Jerusalem, Lod, Natanya, Or Yehuda, Petach Tikva, Ramla, Rishon Lezion, Rehovot, Tel Aviv, and Zefat. Their ages (estimated) were about five percent under thirty, about a third between 30 and 45, and about half over 45. About half were not employed outside the home. About a third emigrated in the 1980s, about 40% in the 1990s, and about a fifth in the first decade of 2000. Most interviews with Ethiopian immigrant participants were conducted in Amharic by research assistants from the Ethiopian immigrant community. Four formats of narrative prototypes were produced (video and print), based on cases described by study participants, and were shown to participants, who were asked to respond and assess them. Data collection and analysis of the findings took place between December 2008 and December 2009. The study had a Steering Committee that consisted of members from five advocacy organizations: The *Tene Briut* organization, The Israel Association for Ethiopian Jews, the Society of Patients Rights, *Yedid*/Association for Community Empowerment, and Physicians for Human Rights. In addition, Steering Committee meetings were attended by members from the Israel AIDS Task Force and *Shatil* organization. Experts from the Clalit Health Fund were also consulted regarding procedures related to health rights.

Difficulties and Barriers in Attaining Health Rights from the Perspective of Ethiopian Immigrants

Nine main issues emerged in the study as barriers to attaining health rights among Ethiopian immigrants: (1) lack of Hebrew language proficiency among the immigrants and limited services that are linguistically accessible; (2) lack of knowledge about particular healthcare rights; (3) lack of knowledge about the hierarchy in the healthcare system; (4) low sense of efficacy to attain the health rights; (5) feeling of discrimination; (6) cultural conceptions, customs, and beliefs; (7) lack of trust in the system; (8) worry that the doctors or the health funds will retaliate if they want to switch to another; (9) no reliable source for health rights information (see Table 1). It should be noted that participants in the study explained that these are mainly true for immigrants who are older, do not have language proficiency in Hebrew, and are less acculturated. However, these barriers were also raised and appeared relevant to participants who were immigrants who were in Israel for several years and were relatively young; for example, a group of women in their thirties or early forties, who had been in Israel about five years, but had low literacy skills in general and were not proficient in Hebrew.

Lack of Hebrew language proficiency among the immigrants and limited services that are linguistically accessible: The most prominent issue that emerged across groups and interviews was the lack of Hebrew language proficiency among the immigrants and limited services that are linguistically accessible. Participants noted that there were few if any materials in Amharic and very limited translation services. Participants were often aware of a healthcare liaison program in several clinics, staffed by trained personnel and sponsored by the Ministry of Health and one of the health funds (Nirel, Rosen, & Ismail, 2000), but they felt it is not sufficient and serves only part of the population that needs it. There is a phone translation service initiated and implemented by the *Tene Briut* organization that is sponsored by foundations and the Ministry of Health. However, this program, although it can be implemented in over 100 clinics, is unable to meet the needs of many of the immigrants in particular because it is not available in all clinics, it depends on the willingness of physicians to use it, it requires additional time (although it can increase efficiency in the long run), and it is not face-to-face, so nonverbal cues cannot be viewed. Another structural issue that was raised was that physician visits are typically limited in time and do not allow enough time for the immigrants to explain their concerns or to ask questions. Participants explained that Ethiopian immigrants may need more time to communicate than others because of their language limitations, in particular regarding medical terms.

Participants mentioned several consequences resulting from the language limitations as these relate to healthcare rights. For example, those who do not know the language are not able to understand what happens in the healthcare system, feel they are unable to challenge the healthcare system, do not ask about medications and treatments, and do not get information about possible alternative treatments.

Issues associated with lack of translation services: Another type of impact associated with health rights is that those who do not know Hebrew, when they need help in translation forfeit their right to privacy and confidentiality, because they agree to have someone, who may be a person who just happened to be in the clinic, serve as a translator. Other issues associated with translations were that those who do not know Hebrew often depend on young people to help in the translation. Yet, this can have a serious negative impact because of several factors: (a) those who do not know Hebrew get into the mode of being dependent and used to relying on the young ones for help; (b) younger people who are used as mediators often are disconnected from the world of the older adults and cannot adequately convey the culturally-related concerns of older or new Ethiopian immigrants to the healthcare providers, or their proficiency in Amheric is limited; (c) some of the young people are ashamed of accompanying their parents or older relatives to the clinics and do not want to take this role upon themselves; (d) there are situations that the mediators/translators do not want to be involved in or do not want to hear details of the health situation or the problems that are going to be discussed.

Lack of knowledge about the rights: In almost all the interviews with the Ethiopian immigrants, participants expressed that they felt they had a lack of knowledge regarding health rights or the specific procedures that are needed to attain them. Most had not heard about various rights when they were told about them, and expressed a desire to learn more.

Lack of knowledge about the hierarchy in the healthcare system: Related to lack of knowledge of the health rights was lack of knowledge about the healthcare system. Ethiopian immigrants may not understand the structure of the health care system as a whole and of the healthcare provider organizations. They do not have the knowledge of the system as a hierarchy, even among the doctors and administrators. Thus, they do not know that if they are dissatisfied with an administrative decision or even a medical one, they can appeal or complain within the clinic and outside it, to a higher authority in the healthcare fund or the Ministry of Health. A related belief was that if they would attempt to change a doctor or a health care fund, they would suffer retaliation. Specifically, they feared that the doctors they left will tell other doctors about them if they will try to switch doctors, or the health fund that they leave for another will take revenge against them.

Low sense of efficacy to attain the health rights: They added that when they do have knowledge about particular health rights, they are not likely to try to realize them, or would not “dare” to challenge the system or people in administrative positions. Thus, not only lack of knowledge of the right was a factor of not attaining it; also when they knew about it, they explained how cultural and social issues serve as barriers.

Feeling of discrimination and lack of trust in the system: A recurring theme that emerged in the personal and group interviews was that Ethiopian immigrants feel they often are not treated nicely by staff members in the clinics. It should be noted that in contrast, some participants felt they were treated very well and had excellent relations with their healthcare givers, but in general the theme of a feeling of discrimination recurred across interviews. One particular issue stated was that Ethiopian immigrants feel they are not examined physically by physicians and some have expressed it by saying "The doctors speak with their computers instead of listening to us.” This they felt was due to discrimination or prejudice. They also felt that their visits to the doctor are shorter than the visits of others. In several interviews participants expressed a belief that they were not receiving medications or treatments that are of the same quality as other Israelis receive. They said, for example, that they are not given the “good medications” but more inferior ones.

Cultural conceptions, customs, and beliefs: Cultural beliefs and conceptions are an important barrier in achieving particular health rights, according to the study’s participants. They explained that deeply ingrained cultural customs of respecting authority and of taking special care not to hurt another person’s feelings may prevent Ethiopian immigrants from realizing particular health rights. For example, Ethiopian immigrants may be less likely to complain or try to attain the rights because of their cultural conceptions that this is not polite and is inappropriate. They are less likely to disagree and even contest what the doctor says, because doctors are perceived as an authority that needs to be adhered to. One belief is that "below God, their lives are in the hands of the doctors”. Further, they may not insist on having their privacy because they respect the doctor, when he or she may do things that violate it.

One cultural conception that may prevent Ethiopian immigrants from trying to change their doctor or health fund, even when they are deeply dissatisfied, is a fear of the unknown, as represented by an Ethiopian saying “The devil I am familiar with is better than the angel I don’t know.” Another issue that emerged was that Ethiopian immigrants felt healthcare providers do not know about their culture and do not respect it.

Lack of trust in the system: In some groups and interviews participants expressed their lack of trust in the system. Some even mentioned the event when it was discovered that there was a policy that the blood of Ethiopian immigrant donors should be discarded, because a certain number of members of this population had contracted HIV. The discovery created a protest and there are still precautionary measures that need to be followed. Participants in the study expressed their lack of trust in the system, even when they themselves may have good relations at the community clinic.

Worry that the doctors or the health funds they want to change will retaliate: A recurring concern that was raised in the interviews was that the Ethiopian immigrants who decided they wanted to switch from one fund to another or change their doctor feared retaliation.

No reliable source: Participants felt that for many Ethiopian immigrants there are no reliable and accessible sources for obtaining information about health rights; there is no one they feel they can ask who can give them the kind of information they need.

Table 1: *Factors perceived as barriers to attaining health rights from the perspective of Ethiopian immigrants.*

Factor	Specific Issues and Problems that Emerge
Lack of Hebrew language proficiency among the immigrants and limited services that are linguistically accessible	– Healthcare services are not accessible in terms of language and culture to many Ethiopian immigrants; there is a lack of materials in Amharic and limited translation services – Doctor visit is typically too short and does not allow enough time to communicate *Impact on the immigrants* – Those who do not know the language are not able to understand what happens in the healthcare system – Those who do not know the language feel they are unable to challenge the healthcare system – Those who do not know the language do not get information about possible alternative treatments – Those who do not know the language do not ask about medications and treatments – Those who do not know Hebrew forfeit their right to privacy and confidentiality when needing a translator *Translator issues* – Need mediators and their dependence on young people – Adults who do not speak Hebrew got used to turning to young people – Younger people who are used as mediators are disconnected from the world of the older people and cannot represent well the culturally related concerns of older or new Ethiopian immigrants to the healthcare providers – Some young people are ashamed of accompanying their parents or older relatives to the clinics There are situations in which the mediators/translators do not want to be involved or do not want to hear details

Factor	Specific Issues and Problem that Emerge
Lack of knowledge about particular healthcare rights	– Lack of knowledge about the supplemental insurance – Lack of knowledge on how you obtain the right in terms of the necessary procedures
Feeling of discrimination	– Ethiopian immigrants feel they often tend not to be treated nicely by staff members in the clinics – Ethiopian immigrants feel they are not examined physically by physicians – Ethiopian immigrants feel doctors do not know about their culture and do not respect it – Ethiopian immigrants assess that their visits to the doctor are shorter than the visits of others – Ethiopian immigrants believe they do not always get the "good medications" but inferior ones
Cultural conceptions, customs and beliefs	– Do not complain or try to attain the rights because of their cultural conceptions that this is not appropriate – Doctors are perceived as an authority that needs to be adhered to – Do not insist on privacy because they respect the doctor – Fear of the unknown – a cultural conception regarding the unknown
Lack of trust in the system	– Do not trust the system and its decision-making process, believe it tries to find ways not to carry out actions that are to the advantage of individuals
Low sense of efficacy regarding the ability to attain health rights	– Low sense of efficacy or assertiveness in "daring to do" – challenge people in administrative positions or the system as a whole – Lack of belief that there is any sense in trying to complain and that they can influence the system
Lack of knowledge about the hierarchy in the healthcare system	– Do not understand the structure of the health care system as a whole and of the healthcare provider organizations – Do not know that doctors are part of a complex and hierarchical organization

Factor	Specific Issues and Problem that Emerge
Worry the doctors or the health funds they want to change will retaliate	– Think the doctors they left will tell other doctors about them if they will try to switch doctors – They think the health fund that they leave for another will take revenge against them
No reliable source	– No reliable and accessible sources for obtaining information about health rights (organizations may be biased)

Issues and Needs Associated with Health Rights that Need to be Addressed According to the Ethiopian Immigrants in the Study

Among the substantive issues that were mentioned in the study, three main issues were emphasized: supplemental insurance, payments, and changing a doctor (see Table 2). Participants explained that they believed Ethiopian immigrants who do not know Hebrew are less likely to purchase the supplementary insurance because they do not understand its benefits, and consequently they need to pay more for particular services or medications. They explained that because in the past Ethiopian immigrants were victims of scams that involved giving a payment order, there are many who are currently suspicious of doing so, and therefore do not agree to get the supplemental insurance. Another related issue was the belief that Ethiopian immigrants feel they often do not understand the payments to the health fund, what they are paying for and which kinds of discounts they can receive, and they do not understand what the health fund organization is supposed to supply. One issue that was specified was that Ethiopian immigrants do not understand when they will or will not be reimbursed for the use of an ambulance. Also, Ethiopian immigrants often do not know about getting discounts for medical equipment or medications.

There was a general feeling that most Ethiopian immigrants are aware of the right to change from one health fund to another, but that the older ones are not likely to do so, even when dissatisfied. Regarding the right to change one's doctor, participants said that many are aware of the right to change their family doctor, but unaware that they can also change a specialist. Several participants said for Ethiopian immigrant women this right may be of particular importance because there are Ethiopian immigrant women who refrain from going to their male gynecologist because of their cultural background, but do not know they can change and go to a woman. This can result in under-diagnosed and under-treated medical conditions.

Table 2: *Issues and needs associated with health rights that need to be addressed according to the Ethiopian immigrants in the study.*

Issue	Particulars
Supplemental insurance	– Ethiopian immigrants who do not know Hebrew are less likely to purchase the supplementary insurance because they do not understand its benefits – Some Ethiopian immigrants are suspicious of giving a payment order (because of bad experiences in the community when they were signed up for things they did not understand and lost money)
Payments	– Ethiopian immigrants feel they often do not understand the payments to the health fund, what they are paying for, and which kinds of discounts they can receive – Ethiopian immigrants do not understand what the health fund organization is supposed to supply – Ethiopian immigrants do not understand the specifications regarding the use of an ambulance – Ethiopian immigrants do not know about getting discounts for medical equipment or medications
Changing a doctor	– Many Ethiopian immigrants are not aware of their right to change a doctor, and when they know about it, they are concerned about doing it because of cultural beliefs. – There are Ethiopian immigrant women who refrain from going to their male gynecologist because of their cultural background, but do not know they can change and go to a woman

A Model for Developing Narratives to Communicate Health Rights Information

A model for developing narratives to communicate health rights information was employed in the study. The model draws on the assumption that communicating to populations with particular cultural beliefs and customs needs to center on their needs and on the guiding principles of social marketing. According to social marketing principles, the development of communication materials should be based on the needs and wants of the intended population and should involve a process of formative evaluation to ensure that the information that is presented can be understood by the populations is it intended for (Gibbs, Sangl, & Burrus, 1996; Grier & Bryant, 2005). Clearly, information about health rights intended for immigrant populations needs to be presented in a language understood by the intended population, should be sensitive to their cultural beliefs, and designed to be understood by people who do not have literacy skills (Marquis, 1983; McCormack, Garfinkel, Hibbard, Kilpatrick, & Kalsbeek, 2001; Root & Stableford, 1999). Even more, as indicated in the findings of this study, it is important to learn, from the perspective of the intended population, what issues related to their rights are important to them and what they feel they need to know (Isaacs, 1996).

Drawing on behavior-change and social marketing approaches, another postulation is that health rights information should address issues conceived as barriers that need to be overcome in order to realize these rights. In this study a series of barriers were identified, which included language and cultural factors as well as a low sense of people's ability to realize their rights. Further, drawing on behavior change approaches, another guiding principle is that the information should reinforce the feeling that people can get support when they have to confront various difficulties when trying to attain their health rights. These assumptions are the basis for five elements we propose are important in the design of health rights information and which can serve as a conceptual model: (1) provision of information about the specific rights and the mechanisms or path to obtain it; (2) noting that attaining the right is not always simple or easy; (3) acknowledging and suggesting possible ways to address barriers that members of the intended population have identified regarding attaining the health right (including culturally-related barriers);

(4) describing or illustrating ways to address barriers and attain the health rights; (5) presenting the possibility of getting assistance or support to realize the rights. It should be noted that the barriers referred to should be those identified in the preliminary process, and should be viewed from the perspective of the intended populations.

Drawing on these principles, four types of prototypes were produced (video and print), based on cases described by study participants, and were shown to participants, who were asked to respond, compare, and assess them. The materials were based on specific stories and examples that emerged in the study. Despite their various limitations, the narrative materials were assessed as informative, culturally appropriate, addressing barriers from "real life", and enhancing efficacy as well as mutual help. Participants who were shown different types of formats tended to prefer the more "entertaining" format that included humor and dialogue.

Channels and Formats for Communicating Health Rights Information

Participants overall liked the prototypes developed in the study, which consisted of video clips and illustrated booklets, and thought each type was appropriate. Those who were presented with the video clips were particularly pleased with the format, because it was lively and entertaining. They felt it was an effective and attractive format. Participants liked the booklets as well, and said they could sit with family members and go over them together. When asked which mass media would be more effective, they suggested that using the radio is highly recommended because many Ethiopian immigrants listen to the Amharic programs regularly. Television was mentioned rarely. Participants recommended that the booklets and the video clips (on DVDs) should be distributed to members of the community, so that people could view them with their families, and that they should be used in workshops.

Conceptions of a Reliable Source on Health Rights Information

The Ministry of Health and non-government organizations were mentioned as reliable sources for health rights information. Participants who saw the booklet that showed people at the ombudsperson's office in the Ministry said they did not know about it, and they were impressed such an office existed, and thought it could be a reliable source. However, some participants raised a few reservations. They suggested that some immigrants confuse the Ministry and the healthcare provider organizations (the health funds), and therefore they may not perceive the Ministry of Health as a reliable source. Non-government organizations were also mentioned as a potential reliable source for information about health rights, but some of the study participants suggested that some of the Ethiopian immigrants may not consider non-government organizations as reliable because they may be perceived as having their own interests. Thus, the credibility of these organizations is an important consideration.

Conclusions and Policy Recommendations

The findings of this study underscore the importance of conducting a study that involved Ethiopian immigrants themselves, which enabled identifying and characterizing cultural and organizational barriers to the realization of health rights among this immigrant population. A major conclusion of the study is that it is feasible and important to conduct a study on how the members of the intended population view issues and barriers associated with attaining health rights from their own perspective. This can enable (a) identifying barriers associated with the healthcare system, as well as (b) barriers associated with the social or cultural characteristics of the population. In this study, Ethiopian immigrants identified several major barriers to the attainment of health rights. Major obstacles noted included language barriers that imposed on them a situation in which adults had to rely on their children to serve as translators; a feeling that caregivers lack an understanding of their culture; their cultural customs and beliefs that inhibit complaining (e.g., it is not polite to complain or to demand, doctors are an authority figure, fear of change); and feelings of discrimination. They also expressed a low sense of self-efficacy in attaining health rights, even when they were aware of specific rights.

These findings indicate that in order to develop information on health rights for minority populations that have low literacy skills and limited proficiency in Hebrew, the approach should address these particular barriers. We conclude with the following recommendations:

1. The development and production of materials on health rights needs to be tailored specifically to the needs and cultural beliefs of members of the minority group and to address logistical and cultural barriers, as identified by them. It is recommended that partners in the development process should include social organizations that work in the community and people in the healthcare system as well as members from the healthcare system, from various levels.
2. Include in the development and implementation process a preliminary study that identifies issues and barriers from the perspective of the members of the population and conduct a formative research and evaluation study.
3. Materials should be based on a model that acknowledges barriers and enhances self-efficacy by showing positive role models.
4. Use narrative formats that are familiar to the members of the population, including stories and examples.
5. Present information about the rights in general, as well as specific examples that illustrate it.
6. Create a resource that will enable members of the population to ask questions in their own language, such as a “hot line”.
7. Address feelings and beliefs regarding discrimination and the specific issues that are raised in this study and other studies.
8. Provide culturally sensitivity training to staff in the healthcare system.
9. Drawing on the current programs of Refua Shlema liaisons in community clinics and the translation system established by Tene Briut, establish comprehensive national professional translation services that will eliminate the need to use family members or acquaintances as translators and infringe on people’s right to privacy and confidentiality in the healthcare system. This system can encompass both face-to-face and phone-based translation services.

10. Conduct additional research on the particular health rights needs of members of the Ethiopian immigrant community and other minority populations.

11. Adapt and apply the model of communication about rights using the model from this study to other topics.

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Maternal Beliefs and the First Visit to Mother and Child Health Clinics among Bedouin Mothers in Southern Israel

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Introduction

Well infant care is defined as a "subcomponent of primary care for children that includes in addition to well-child care also acute and chronic care, coordination and follow-up for developmental problems" (Kuo et al., 2006). Well infant care is considered a cost saving health service and essential for a child's healthy growth and development (Margolis, 2004). Studies on the different components of well infant health care services have shown that vaccinations (Jefferson, Rivetti, Harnden, De Pietrantonj, & Demicheli, 2008), universal hearing tests (Thompson et al., 2001; Wolff et al., 2010), and different developmental tests (Mahan, Katz, & Kim, 2009), are generally cost-effective. Researchers argue for the need to expand well infant care to include more health-promoting activities rather than the traditional immunizations and developmental follow ups (Schor, 2004). The American Academy of Pediatrics (AAP) includes well infant care service (American Academy of Pediatrics and Committee, 2008; Schor, 2004) based on the "Bright Futures" Children's Health Charter (Hagan, Shaw, & Duncan, 2008). In many countries, well infant care services are provided in the community by Maternal and Child Health Clinics (MCHC); however, countries vary in the structure of the services and the way these services are delivered, type of follow ups, the health professionals who are responsible for providing the services, and the timing of the routine visits to the MCHC (Kuo et al., 2006). The current paper focuses on the timing of the first visit to the MCHC.

The first contact with health care services after birth is considered a cornerstone and a gatekeeper for other health care services infants might need at this age (Kuo et al., 2006). Many health problems that are detectable at this age have a better prognosis if treated as early as possible. In the United States, The American Academy of Pediatrics (AAP) recommends that the baby should be screened within the first 3-5 days after birth by a pediatrician (American Academy of Pediatrics and Committee, 2008). In the United Kingdom, the NHS recommends newborn physical examinations within the first 6-8 weeks of life (Shribman and Billingham, 2008).

At the first visit to the MCHC, assessment of the baby's weight, height, and head circumference is made and serve as reference for future monitoring of growth and development. Parents are instructed regarding breastfeeding, nutrition, immunizations, and sleeping position, and parents' concerns are discussed. Consequently, a timely first visit to the MCHC can serve as an important indicator for well baby care as it has significant implications for future health development, in addition to a timely routine of recommended checkups and immunizations. Late first visit to the MCHC might lead to unnecessary delay in the immunizations program and late diagnosis of health problems for which early detection is important.

In Israel, initial newborn screening is performed by a pediatrician in the hospital after birth, and blood samples are drawn to screen for various inborn errors of metabolism (PKU, hypothyroidism, etc). Subsequent exams are detailed in the guidelines issued by the Director of Public Health Services (Ministry of Health, 2004). Costs of hospital delivery and newborn screening are covered by National Health Insurance and the Ministry of Health, respectively. Upon discharge the mother gets a letter in which she is referred to the MCH clinic near her place of residence. Parents are advised to bring their infants to the MCHC for the first time when they are two weeks old. At the first visit the nurse registers the baby and advises parents regarding growth and development, breastfeeding or healthy food, safety, oral health, prevention of communicable diseases, folic acid uptake, baby positioning and immunizations. Baseline weight, height, and head circumference are assessed. When necessary, a home visit is scheduled. At the first visit to the MCH the nurse also schedules a pediatrician checkup (usually at the age of one month; Ministry of Health, 2004). Until recently, well-baby follow up in Israel, including most immunizations, required a semi-annual payment per family (about $50).

A study conducted in 2000 in Israel with a sample of 1100 mothers from large towns in Israel (more than 50,000 inhabitants, which mostly do not include Arab populations), showed that 50% of the Jewish, but only

19% of Arab, women brought their infants to the MCHC for the first visit within the first two weeks of birth (Palti, Gofin, & Adler. 2004). However, less is known about the factors contributing to late first visit to the MCHC among Arab mothers. In the Negev, as a result of a severe shortage of nurses, mothers are scheduled to come for the first visit around the time of first immunization - at the age of 1-2 months. In the present study we set out to assess the timing of the first visit to the MCHC and the factors associated with it among Bedouin-Arab mothers in the Negev area of southern Israel.

The Bedouin of the Negev in Southern Israel

Bedouins in the Negev constitute 12% of the Palestinian Arab minority - which comprises 18% of the total population of Israel - and about 25% of the total population in the south (Center for Bedouin Studies, 2004). They are a young population (median age = 12.7 years) with high fertility rates (total fertility rate = 7.1; Central Bureau of Statistics, 2007).

Bedouins are considered an indigenous minority since they have lived in the Negev area in the south more than six centuries before the establishment of the state of Israel in 1948 (Meir, 1997). Like many indigenous groups worldwide, they are still struggling for equality and recognition, and preservation of their culture and tradition. The Israeli governments have been encouraging them to settle in permanent townships, but only about half of the population moved while the rest are determined to keep their own lifestyle and with that also the lands on which they traditionally lived. This has led to an unresolved dispute over land ownership with the government, resulting in localities that are officially "unrecognized". In 2008 about 50% of the Bedouins lived in these unrecognized localities, characterized by lack of basic infrastructure such as tap water, electricity, sewage disposal, paved roads, and public transportation (Boteach, 2008). Since 1995, all Bedouin infants and children have been entitled to health care services according to the National Health Insurance Law, but there are geographic access barriers to care for those living in unrecognized localities.

In the past, Bedouins led a semi-nomadic lifestyle, earning a living from agriculture and herding sheep (Lewando-Hundt et al., 2001). They lost their main source of livelihood after massive confiscation of lands by Israel governments since 1948 (Boteach, 2008). This was accompanied by tremendous changes in the social and economic structures of the society. Nowadays, most Bedouins hold unskilled jobs and are among the most disadvantaged population group in Israel. On average, they are of low education level, 45% of the mothers and 34% of the fathers of children registered in local MCHCs had 0-6 years of education (Ministry of Health, 2008). Despite many transitions in different aspects of life, Bedouins still keep traditional lifestyles; they are a collective tribal society with strong extended family ties. Patriarchy and lower status of the women have encouraged and sustained a high rate of cousin marriages and polygamy (Lewando-Hundt et al., 2001). It is estimated that about 25% of all marriages are polygamous, with adverse influences on women's mental health (Al-Krenawi & Graham, 2006) and on children's psychosocial indicators and achievements in schools (Al-Krenawi & Graham, 2006; Elbedour, Onwuegbuzie, Caridine, & Abu-Saad, 2002). Consanguineous marriages - estimated to be 60% of all marriages (The Galilee Society, 2004) - are associated with a greater percentage of congenital malformations and genetic disease resulting in infant mortality and morbidity (Ministry of Health, 2008).

Maternal and child preventive services for all residents of Israel, including the Bedouins, include prenatal care, well-baby care including developmental follow-up, screening tests, anticipatory guidance, and immunizations provided mainly by the Ministry of Health through local MCHCs (Lewando-Hundt et al., 2001). Even though the preventive and primary health care services are included in the basic basket of the National Health Care Services, until its cancellation in 2010, a per-family fee was required every six months for MCHC services. Co-payments for medications and other special health care services pose financial difficulties on the large Bedouin families (Beckerleg, Lewando-Hundt, Belmaker, Abu-Saad, & Borkan, 1997). While basic health care services are provided to the Bedouins, health gaps remain between Bedouin infants and infants in other subgroups of Israel society. While declining over the years, Bedouin still have the highest infant mortality rate in Israel (Ministry of Health, 2008). Rates of infectious diseases and hospitalization (Levy, Fraser, Vardi, & Dagan, 1998), anemia and iron deficiency (Urkin, Weitzman, Gazala, Chamni, & Kapelushnik, 2007), low birth weight (less than 2500 g), and stunting (Ministry of Health, 2008) are higher than those of the Jewish population in the Negev.

Maternal Health Beliefs and Child Care

The Health Beliefs Model (HBM) framework was developed to explore factors associated with utilization of preventive health care services such as screening tests and immunization (Rosenstock, 1974). The HBM postulates that individuals are more likely to undertake a health behavior when they have stronger perceptions of disease severity, greater perceived susceptibility to the disease, believe that undertaking the behavior will be of benefit to their health, and perceive that barriers to the health behavior are low. Cues to action might also relate to performing a health behavior as it indicates an external or internal motivation to comply. Self-efficacy was added more recently to the HBM (Becker & Maiman, 1975) and it refers to the person's belief in their own ability to perform the behavior change.

Although many studies used the HBM framework to study perceptions and attitudes regarding health behaviors and compliance with use of preventive services, very few studies examined the effect of maternal beliefs on infant care using the HBM (Bates, Fitzgerald, & Wolinsky, 1994).

The aim of the current study was to examine the associations between timing of the first visit to the MCHC and maternal health beliefs (HBM) on infant care and whether adjusting for structural factors (living conditions, socio-economic status, cultural, accessibility to the MCHC), and birth factors will change this association.

Methods

Data Collection

This cross-sectional study was conducted between June 2007 and January 2008. The study population included Bedouin mothers of full-term babies (37 weeks or more) who visited one of 14 MCHCs during the seven months of the study. The clinics were selected to represent both recognized and unrecognized localities. Mothers were personally interviewed using structured questionnaires in Arabic by local lay health advisors who speak the women's mother tongue, and were trained as interviewers. All mothers who arrived at the MCHC were approached and if they had a 9-15-month-old infant they were asked to participate in the study. Eligible mothers who agreed to participate were interviewed after having signed or finger stamped an informed consent form agreeing to be interviewed and allowing access to their infant's health records. The interviewer read the informed contest form for most of the mothers, since many of them were illiterate. Data were also collected from the babies' files in the MCHC by the research coordinator. The study was approved by the Institutional Ethics Committee of Soroka University Medical Center after receiving permission from the Ministry of Health Southern Health District to conduct the study at the MCHCs.

The Study Sample

A total of 1175 mothers were consecutively approached, 587 were eligible to participate. Among them 505 (86% response) agreed to be interviewed. Of the 505 mothers interviewed, 464 mothers of full-term babies formed the final study population. The number of mothers sampled from each MCHC was proportional to the size of the clinic. The baseline demographic data of average age of the mothers, average number of children, and percent of low birth weight infants of the mothers in the study were very similar to those of the general population of Bedouin mothers attending the MCHCs during 2007 (based on personal communication from Dr. Belmaker, 2010).

The Study Measures

Data on the dependent variable *timing of the first visit* were obtained from the infant's files at the MCHC.

The Health Beliefs Model variables are subjective beliefs of the mothers regarding infant care. The model includes subscales that emerged from prior stages of the study that included conducting 10 focus groups with 106 mothers from 10 localities; results of the focus groups were used to construct a questionnaire that was validated using factor analysis and then examined for reliability.

Eight subscales emerged instead of six subscales in the original model (Daoud, Agbariah, Belmaker, Adler, & Shoham-Vardi, in preparation). The internal consistency of the eight factors (HBM subscales), assessed by Cronbach's alpha was high (0.66-0.84) except for the self-efficacy factor, which had moderate internal consistency (Cronbach's alpha = 0.57; Table 3). The subscales were as follows:

Perceived severity: a list of health problems were raised by the mothers in the focus groups and was converted into questions about the severity of several health conditions. For example, "To what extent is 'high fever for more than one day' a severe problem for an infant?" The response categories were: 1-Not at all, 2-Slight, 3-Small, 4-Moderate, 5-Severe, and 6-Very severe.

Perceived susceptibility: a parallel set of questions was asked about the mothers' perceived likelihood of their babies being affected by a health problem from the previous list. For example, "To what extent are you worried that your baby will have a fever?" Six response categories included: 1-Not at all, 2-Slight, 3-Small, 4-Moderate, 5-Severe, and 6-Very severe.

Perceived barriers: questions regarding the extent to which each of the barriers mentioned in the focus groups represented a problem for the mother in providing care for her infant. The response categories were 1-Not at all, 2-Slight, 3-Small, 4-Moderate, 5-Severe, and 6-Very severe. Example: "How much is the distance from the MCHC a problem for you?" In the factors analysis the list of 14 barriers formed two groups: living conditions variables and financial and cultural barriers.

Perceived benefits of infant care practices: the extent a mother agrees with statements regarding gaining benefits from specific infant care practices. For example: "How likely is breastfeeding to help prevent disease?" and "how likely are immunizations and checkups in the MCHC to help in disease prevention for your baby?" Six response categories included; 1-Not at all, 2-Slightly, 3-A little, 4-Moderately, 5-Very much, and 6-Extremely. In the factors analysis the perceived benefits of care were divided into two subscales: modern and traditional benefits. The traditional care included perceptions of the mothers regarding traditional practices (such as washing the baby, swaddling in a traditional way) while the perceptions of modern care included practices included in the recommendations of the MCHC (sleeping position, toys, using safety seats).

Self-efficacy: the extent to which the mother agrees with three statements: a. I can provide my infant with his or her needs in an optimal way, b. I can prevent my infant from becoming sick, and c. it is possible to prevent disease among babies. The six response categories ranged from 1-6 from strongly disagree to strongly agree.

Locus of control: Measured by four statements concerning religious beliefs about preventing disease, injuries, and other health problems. For example, “Only God can prevent the baby from becoming sick.” The response scale of six categories ranged from strongly disagree to strongly agree.

Since many mothers were illiterate and not familiar with Likert scale format, we prepared a graphical representation of six steps to illustrate the ordinal levels of the response categories. Mothers were asked to point to the level of agreement on the drawing.

Independent Control Variables

a. **A group of structural variables** that were more objective variables, mostly not controlled by the mothers but inherent to the mother’s social and physical environment;

   Living conditions included questions on the legal status of the locality (recognized or not), and if the household is connected to the national electricity system and has a constant supply of running tap water.

   The socio-economic status: The mother's and father's formal years of education were obtained from the MCHC infant register. The mother was asked questions on the main source of income in the family (social security or work), on her and her husband’s current employment status (yes or no), and her literacy in Arabic (reading and writing).

   Accessibility of MCHC was examined by two questions: *a. presence of MCHC at the locality* obtained from the infant registry at the MCHC and from asking the mother, and *b. the length of time to reach the MCHC.*

   Cultural factors: *1. Consanguinity* was obtained by asking the mother if she is married to a relative and if he was a first cousin. 2. *Polygamy* was determined by asking if her husband was married to other women.

b. **Pregnancy and birth factors:** two variables that were obtained from the infant register in the MCHC included the number of children the mother had including this baby, and the birth weight of the infant, which the MCHC nurses usually copied from the birth discharge record.

c. **The demographic variables** including mother's age (collected from the MCHC file and calculated based on the year of birth) and a self-reported country of birth (Israel or other).

Data analysis

After examining the distribution of the timing of the first visit to the MCHC, it was dichotomized using the mean as the cutoff point (as the median and the mean were very close). Bivariate associations were examined between each of the HBM subscales, independent variables, and the time of the first visit to the MCHC.

Two multivariate logistic regression models were used in the final analysis of the timing of the first visit. Model 1 included only the HBM constructs that were significantly associated with the timing of the first visit in the bivariate analysis. In model 2 other independent variables that were significant in the bivariate associations were introduced in model 1.

To avoid multicolinearity in the multivariate analysis, we examined the correlations between the variables before including them in the models. The variables type of building and connection to electricity were not included since both had high correlations with the legal status of the locality.

Results

The distribution of the study population is shown in Table 1; most mothers were younger than 28 years of age. The mean age of the mothers was about 27.9 (SD±6.0), range 18-49 years. Approximately 60% reported consanguineous marriage and about 22% polygamous marriage. Harsh living conditions were reported; one-third of the mothers reported living in unrecognized localities and having no connection to the national electricity grid and about 35% reported living in temporary dwellings (tents or tin shacks).

Most mothers were of low socio-economic status; about 40% reported that the family's main source of income was social benefits, less than 25% reported that their family own lands. Most mothers were unemployed. Formal education of both the mother and husband was low and about 30% of the mothers were illiterate.

The mean number of children for the mothers in the study was 3.98 (SD±2.77), range 1-14. About 24% of the infants in the study were the first child while about 36% were the fifth child or more. About 10% of the infants had low birth weight (<2500 g), even though they were born full term (37 weeks or more). About one-quarter of the mothers reported not having an MCHC in their localities, and that it took them more than 30 minutes to reach their MCHC.

The mean of the first visit time was 42 days (SD±26.2, range 0-332 days, median=38 days). Only 10.1% of the mothers came with their infants to MCHC for the first visit within the recommended first two weeks after birth, 74.4% came more than 30 days from birth, but about 54% of the mothers brought their babies within the first 40 days after birth (Figure 1).

In the bivariate associations (Table 2), timing of the first visit to the MCHC was significantly associated with some of the living conditions variables, socio-economic status, and time to reach the MCHC. Coming for the first visit more than 42 days after the birth of the baby was significantly associated with residing in a legally unrecognized locality, temporary type of house, house not connected to electricity, landownership, unemployment, illiteracy, and living 30 minutes distant from the MCHC. No associations were found with the mother's age or the cultural, or pregnancy, and birth factors considered.

Examining the associations between the mother's health beliefs (HBM) about infant care and the first visit to the MCHC (Table 3) indicated that lower perceptions of benefits of modern infant care, higher perceived barriers of living conditions, and higher external locus of control, were significantly associated with late first visit (more than 42 days).

The first multivariate model (Model 1 - Table 4) included only the mother's beliefs on infant care (HBM subscales) that had significant associations with first visit in the bivariate associations. The results show that only perceived barriers of living conditions and perceived benefits of infant care remained significantly associated with the first visit to the MCHC. Mothers with greater perceived barriers of living conditions were 1.3 times more likely to bring their infants late to the MCHC first visit (OR=1.3, CI=1.14, 1.48); mothers that reported lower perceived benefits of modern infant care tended to bring their infants late to the MCHC first visit (OR=0.73, CI=0.53, 1.01).

When the group of structural variables were introduced to Model 1 (Model 2, Table 4), the association with perceived barriers of living conditions was strengthened and the association with perceived benefits of modern infant care was attenuated and ceased to be significant. Greater perceptions of the living conditions barriers among the mothers was associated with about 1.32 the odds to carry out a late first visit to the MCHC among the mothers (OR=1.32, CI=1.11, 1.56).

Discussion

This is the first study to report on the time of first visit to the MCHC among newborn infants of Bedouin mothers in southern Israel. It shows that Bedouin mothers brought their infants late to the first visit to the MCHC. Only 10% of them carried out the first visit within the recommended first two weeks of life. This is mostly explained by the fact that the MCH services in the Negev have been suffering from increasing nursing shortages over the past several years, leading to a situation in which there are not enough open appointments for well-baby care for healthy infants before one month of age. Appointments at less than 1 month of age are usually reserved for high-risk infants for whom early first visits to MCHC are particularly important. We therefore defined late first visit as a visit >42 days after birth, which was found to be in our data the mean of the distribution of child's age at first visit. This is actually very far from the recommended 14 days by the MOH and from the findings of a previous study in which 19% of Arab mothers and 50% of Jewish mothers were found to have carried out the first visit to the MCHC within the first 14 days after birth (Palti et al., 2004).

The main factor of the HBM subscales that was associated with a late first visit to the MCHC was perceived barriers of living conditions. These barriers, together with socio-economic and accessibility variables, attenuated the mother's perceived benefits of preventive health care services.

The perceived living conditions barriers included distance from the MCHC, no public transportation, no electricity at home, and living in a house designated for demolition. These barriers were identified by the mothers in the first stage of the study during focus group discussions (Daoud et al., in preparation). It is most likely that mothers' perceptions indicate actual or objective barriers. For example, accessibility of the MCHC was important. The bivariate associations showed that mothers who can reach the MCH clinic in 30 minutes are more likely to carry out a late first visit than mothers who could reach the MCHC in less than 30 minutes, or mothers who live farther away. The time it takes the mother to reach the MCHC is probably not only an indicator of geographical distance but rather an indicator of complex socio-cultural barriers. It is possible that women who live within a short walking distance from the clinic (<30 minutes) and those who need transportation because they live farther away (>30 minutes) find it less difficult to access the MCHC than women who live within a long walking distance (30 minutes). Walking a long distance to the MCHC might require getting permission from the husband and finding a chaperone, who is not always available,. It is also possible that mothers wanted to protect their infants from being exposed to the cold or heat as they have to carry them in an open area for 30 minutes.

Although these barriers are more likely to occur in the unrecognized localities, mothers from recognized localities might also have faced them. Minority mothers in many countries face different types of barriers and challenges trying to provide optimal care for their infants (Flores & Vega, 1998). For policy makers these results indicate the necessity of decreasing these barriers so that the mothers will be able to bring their infants on time to the first MCHC visit.

In addition to these barriers, there might be other factors that would influence the mother's decisions regarding the time of carrying out the first visit to the MCHC that we did not examine in this study. One factor could be related to the 40 days of confinement in this population, during which the Bedouin mothers remain secluded from others and do not leave the house with the baby (Forman, 1990). The 40 day rest at home after birth is known in many cultures in Asia, Latin America, and Muslim Arab countries (Winch et al., 2005). The purpose of the 40 day home confinement is to give the mother and baby a period of rest and adaptation after birth. In the current study, it seems that the "40 days" traditional practice has not been totally abandoned; about half of the mothers carried out the first visit to the MCHC after the first 40 days after the birth.

However, the fact that more than half of the mothers (54%) brought their babies within the first 40 days after birth might indicate a shift from the tradition of 40 days. Previous studies of the Bedouin population conducted in 1990 (Forman et al., 1990) and 1997 (Beckerleg et al., 1997), showed changes in the type of help in the household chores provided to the mothers by other women after birth. Lack of support after birth might lead to that mother's return to the usual routines earlier than in the past (Beckerleg et al., 1997; Forman et al., 1990). Therefore, mothers are more likely to carry on with other non-traditional infant care practices including taking the infant to the MCHC before the end of the 40 day confinement.

Notably, the 40 day confinement was not raised by the mothers as a factor that influenced the infant care practices in the first stage of the current study (in the focus group discussions that were conducted with 106 mothers from 10 localities in order to raise themes that relate to infant care and accord with the HBM; Daoud et al., in preparation). It is possible that at the time of the study, 9-15 months after birth, keeping the 40-day confinement period after birth was not perceived by the mothers as relevant to infant care practices. Moreover, it might reflect an attitude that the timing of the first visit is not important as long as the baby is eventually brought in and given the immunizations; the first immunization the infant gets in the MCHC is at the age of one month.

Our data seem to indicate that Bedouin mothers, who face many barriers to get health care for their infants, may not consider an early first visit a priority in caring for their infants. This might reflect not only the actual perceived barriers to care but also a basic lack of understanding of the importance of a keeping a schedule of timely visits and its impact on immunizations, developmental follow up, and early detection of physical or cognitive health problems. This is evident from the association of late first visit with illiteracy. Literate mothers have more exposure to written materials on the importance of timely well infant care procedures.

It should be stressed that most mothers believe that immunizations, for example, are necessary, but they may delay the first visit as a strategy of coping with the many demands and barriers they face. When making decisions about child care they may not consider timeliness important as long the infant eventually gets the treatment. This personal coping strategy might get some legitimization from MCH services' strategy of delaying the time of first visit as a way to cope with the shortage of nursing staff.

Conclusions

Equitable health policy is usually formulated to make the best use of usually scarce resources to provide quality and accessible services to the target population. As for the Bedouin mothers in the Negev, our findings indicated that recommendations for conducting the first visit within the two weeks after birth are difficult to be followed; moreover, about half the mothers did not conform with the later date of first visit at the age of one month. Delay of the first visit beyond 6 weeks was associated mainly with maternal perceived barriers of living conditions.

Policy interventions to promote a timely first visit have to address the problems of both the population and service providers. Effective ways need to be developed to communicate, especially to the significant segment of mothers who are illiterate, the general importance of preventive health care services and specifically the importance of keeping the recommended schedule of visits to the MCHC. It is essential to include mothers and community leaders in the necessary process of developing solutions and coping strategies with issues mothers perceive as the barriers to care. At the same time, it is necessary to expand local MCHC clinics, staff coverage, and clinic hours in order to facilitate the ease with which appointments can be made for the first visit for this population.

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Appendix

Table 1: Distribution of the study variables.

	% (N)
Mother's age, yrs (N=457)	
18–27	55.4 (253)
28–37	36.8 (168)
38+	7.9 (36)
Cultural factors	
Consanguinity (N=461)	
No	40.1 (185)
Yes, cousin or other	59.9 (276)
Polygamy (N=461)	
Yes	21.7 (100)
No	78.3 (361)
Living conditions	
Legal status of the locality (N=464)	
Recognized village	66.8 (310)
Unrecognized	33.2 (154)
Building type (N=460)	
Temporary (tent or tin shack)	34.6 (159)
Regular	65.4 (301)
Household connected to electricity (N=460)	
Yes	66.1 (304)
No or Not consistently	33.9 (156)
SES of the household	
Main source of income (N=464)	
Work + other	60.3 (280)
Social benefits	39.7 (184)
Land ownership (N=460)	
Yes	24.8 (114)
No	75.2 (346)
Father's years of formal education (N=464)	
0–8	18.3 (85)
9–11	25.4 (118)
12	40.9 (190)
13+	15.3 (71)
Mother employed (N=460)	
Yes	12.4 (57)
No	87.6 (403)
Mother's years of formal education (N=457)	
0–6 years	26.2 (121)
7–9 years	24.7 (114)
10–12 years	33.4 (154)
More than 12 years	15.6 (72)

Table 1: *(continued)*

	% (N)
Mother literate in Arabic (N=459)	
Yes	68.0 (312)
No	32.0 (147)
Pregnancy and birth factors	
Weight at birth (N=443)	
<2500 gr.	9.9 (44)
2500–3500 gr.	77.2 (342)
>3501 gr.	12.9 (57)
Birth order of the infant (N=463)	
1	24.4 (113)
2–4	40.4 (185)
5+	35.6 (165)
Accessibility to health care services	
MCH at the locality (N=460)	
Yes	74.3 (342)
No	25.7 (118)
Time to reach the MCHC (N=458)	
More than 30 minutes	9.8 (45)
30 minutes	14.2 (65)
Less than 30 minutes	76 (348)

Table 2: *Associations between independent variables and time of first visit to the MCHC among Bedouin mothers.*

	N	First visit ≤42 days %	 >42 days %	p value
Mother's age (yrs)				
18–27	243	56.5	43.5	0.433
28–37	168	61.9	38.1	
38+	36	52.8	47.2	
Structural variables				
Cultural factors				
Consanguinity				
No	185	58.4	41.6	0.215
Yes, cousin	161	62.7	37.3	
Polygamy				
Yes	100	52.0	48.0	0.145
No	361	60.1	39.9	
Living conditions				
Legal status of the locality				
Recognized village	310	61.9	38.1	0.029
Unrecognized	154	51.3	48.7	
Building type				
Temporary	159	49.1	50.9	0.002
Regular	301	63.8	36.2	
Household connected to electricity				
Yes	304	64.8	35.2	0.0001
No or not consistently	156	46.2	53.8	
SES of the household				
Main source of income				
Work + other	280	58.9	41.1	0.778
Social benefits	184	57.6	42.4	
Land ownership				
Yes	114	46.5	53.5	0.003
No	346	62.4	37.6	
Father's years of formal education				
0–8	85	49.4	50.6	0.062
9–11	118	60.2	39.8	
12	190	64.2	35.8	
13+	71	50.7	49.3	
Mother employed				
Yes	57	70.2	29.8	0.051
No	403	56.6	43.2	

Table 2: (continued)

		First visit		
	N	**≤42 days**	**>42 days**	**p value**
		%	**%**	
Mother's years of formal education				
0–6 years	121	51.2	48.8	0.125
7–9 years	114	55.3	44.7	
10–12 years	154	63.0	37.0	
More than 12 years	72	65.3	34.7	
Mother literate in Arabic				
Yes	312	62.5	37.5	0.009
No	147	49.7	50.3	
Accessibility of health care services				
MCH at the locality				
Yes	342	59.4	40.6	0.515
No	118	55.9	44.1	
Time to reach the MCHC				
More than 30 minutes	45	62.2	37.8	0.027
30 minutes	65	43.1	56.9	
Less than 30 minutes	348	60.6	39.4	
Pregnancy and birth factors				
Weight at birth				
<2500	44	61.4	38.6	0.590
2500–3500	342	59.4	40.6	
>3501	57	52.6	47.4	
Birth order of infant				
1	113	61.1	38.9	0.820
2–4	185	57.8	42.2	
5+	165	57.6	42.4	

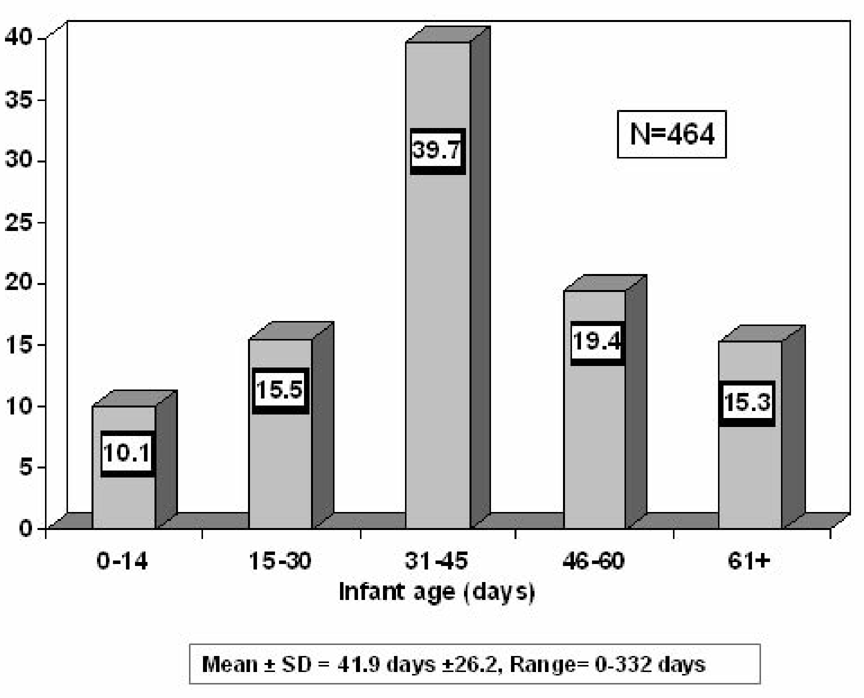
Table 3: *Associations between timing of the first visit to the MCHC and Bedouin mothers' health beliefs on infant care (HBM).*

	≤42 days		**>42 days**		
Mothers' health beliefs on infant care (HBM)	**N**	**Mean (±SD) range**	**N**	**Mean (±SD) range**	**p value**
1 – Severity of disease and safety problems	269	5.38 (±0.46) 1.00–6.00	193	5.35 (±0.61) 1.00–6.00	0.614
2 – Benefits of modern infant care (MCHC recommendations)	270	5.29 (±0.54) 2.71–6.00	192	5.15 (±0.68) 2.71–6.00	0.021
3 – Barriers of living conditions	270	2.14 (±1.33) 1.00–6.00	193	2.82 (±1.70) 1.00–6.00	0.000
4 – Financial and cultural barriers	270	2.07 (±1.34) 1.00–6.00	193	2.23 (±1.37) 1.00–6.00	0.222
5 – Susceptibility of the infant to health problems	269	4.87 (±0.59) 2.17–6.00	193	4.84 (±0.56) 2.17–6.00	0.620
6 – External locus of control	250	4.39 (±1.15) 1.00–6.00	180	4.64 (±1.14) 1.00–6.00	0.021
7 – Benefits of traditional infant care	270	3.94 (±1.39) 1.00–6.00	193	3.99 (±1.46) 1.00–6.00	0.670
8 – Self-efficacy	270	4.17 (±0.76) 2.00–6.00	193	4.07 (±0.79) 2.00–6.00	0.189

Table 4: *Multivariate logistic regression models, odds ratios and confidence intervals of late first visit (>42 days) to the MCH among Bedouin mothers (N=456).*

	Model 1		**Model 2**	
	OR (95% CI)	**p value**	**OR (95% CI)**	**p value**
Mothers health beliefs on infant care (HBM)				
Perceived barriers of living conditions	1.30 (1.14, 1.48)	0.000	1.32 (1.11, 1.56)	0.001
Perceived Benefits of modern infant care	0.73 (0.53, 1.01)	0.059	0.85 (0.60, 1.20)	0.343
External locus of control	1.11 (0.92, 1.33)	0.267	1.07 (0.88, 1.29)	0.495
Structural factor				
Time to reach the MCHC				
More than 30 minutes			0.58 (0.27, 1.25)	0.163
30 minutes			1.61 (0.86, 3.00)	0.136
Less than 30 minutes			1.00	
Literate – Reading Arabic				
Yes, knows well			0.78 (0.48, 1.27)	0.318
No, don't know			1.00	
Employment				
Yes			0.85 (0.44, 1.65)	0.635
No			1.00	
Land ownership				
Yes			2.04 (1.25, 3.35)	0.005
No			1.00	
Legal status of the locality				
Recognized			1.38 (0.82, 2.31)	0.223
Unrecognized			1.00	

Figure 1: *Time of the first visit to the MCH clinic after among Bedouin mothers.*



Towards a Working Definition of Morality in Public Health

Eric Brunner, Sridhar Venkatapuram

Introduction

There are two key applications of ethical values at the public health policy level. One relates to provision of health care with respect to the ability of citizens to pay. The other relates to addressing the uneven distribution of health capability (or Marmot's *causes of the causes*) across a population, or the social body. This chapter explores some of the values and principles related to the second application, that of socioeconomic inequalities in health capability. Recent macroeconomic shocks and their consequences draw attention back to this much disputed ground, including the issue of the effects and acceptability of income inequality and other underlying debates about what constitutes fairness in public health policy.

The consideration of what the right and necessary social response should be in relation to inequalities in health achievements is a necessary and useful activity. Around the world, there is broad agreement that health care provision is a core responsibility of political systems. A state unable to manage a framework for universal health care, whether directly or indirectly delivered, is marked out as a state in need of reform. In the United States, it is evident that resolving the problems with the health care system, including the lack of health insurance for millions of citizens, is as important as finding resolutions in the wars being fought. This level of urgency, however, is at far remove from the issue of pursuing equitable health capability, despite any parallel that may be made with access to health care. The paradox is little discussed, even among those who have made health policy their stock in trade.

This chapter takes as read the body of scientific evidence concerning the wider social determinants of health. There is a mass of studies showing the causal importance of social determinants such as housing, sanitation, childhood circumstances, education, and employment conditions for health (Berkman & Kawachi, 2000; Marmot, Friel, Bell, Houweling, & Taylor, 2008; Marmot &Wilkinson, 2006). These and other infrastructural and social domains are the foundations of *health capability*, variously defined as a combination of *the conditions that affect health together with the ability to act on informed health choices*. The extent of responsibility of the state in providing the conditions for health capability across the population is the subject of our thinking. At a basic level, we ask how can we think about public health morality, and what language could help us to move the discussion forward.

A vital part of the relevant epidemiological landscape is the persistence of social inequalities in health. With or without equity in health care provision, a social gradient of inequalities in morbidity and mortality is observed in all countries where population-based data have been collected. With very few exceptions by cause, rates of adverse health outcomes are lowest in the highest socioeconomic group, increasing stepwise to the lowest social stratum, where the rates are highest. The universality of such observations – in low, middle, and high income countries alike – points to the fact that poor health in a population is not only the consequence of absolute poverty. And the social gradient would not exist if health was determined just by individual behavior or human biology. Inequalities in health outcomes reflect the inequalities in health capabilities determined by the combination of individual biology, behaviors, material resources, and social environments. Inequalities in health capabilities thus reflect societal and individual determinants: the (1) availability of and access to public resources (the social wage), (2) wealth and income, and (3) psycho-social environments at the societal level that are enmeshed with the responsibilities and abilities to protect and promote health located within individuals and families.

Regardless of the country in question, manifestation of health inequalities by social or ethnic category depends on history. The issue here, whatever the precise circumstances that gave rise to present inequalities, is whether there is a clear case to address by means of structural change. This is not a simple issue, since identifying what, where, and how a society must act through social policy involves consideration of what constitutes a *just society*. The difficult issues implicated in such an exercise range from identifying the problem with the causes, distribution and consequences of health inequalities across individuals and populations, the identification of relevant agents and their responsibilities, and justification or moral motivation for enforcing related rights and responsibilities. John Rawls, the prominent liberal philosopher, has been a highly influential thinker and shaper of the concept of social justice in the past four decades. In particular, Rawls offers a justification for social and economic inequality based on fairness and the difference principle. Especially, but not only, in the context of the present Great Depression, Rawls' dominance is challenged on the practical basis that a society that fosters manifest injustice is ipso facto not doing its job properly.

Feeling and Thinking about Justice

It seems fairly uncomplicated to arrive at moral and political conclusions about stark issues of justice and progress. Slavery, oppression of women, systematic medical neglect, torture, and famine arouse strong empathic emotions. The signal is clear because we would much dislike being on the receiving end of such privations. While there is much philosophy that aims to highlight the disjuncture between emotions and reason, moral reasoning about such manifest injustices seems likely to be congruent with emotions. A fairly recent case is the abolition of apartheid. Few of us experienced disparity between our moral perceptions and emotional responses to news of its abolition. Indeed, we are likely to label an individual who did not think that the abolition of apartheid was right as having either an impoverished soul or some major vested interest in the old system.

This framework for pursuing the connection between feeling and reasoning about justice has continuity back at least to the 18th century. European Enlightenment thinkers such as Adam Smith (1723-1790) emphasized tolerance, reason, and liberty in their perspectives. Complexity emerges in his thinking about right and wrong in the public and political sphere when there have to be attempts to balance self-interest, fairness, and social progress. Although better known for The *Wealth of Nations* (1776), his first book, *The Theory of Moral Sentiments* (Smith, 1759), tackled the "human nature" problem in personal and corporate exchanges by applying reasoning to recognize and elaborate on perceptions of moral and material value. Many incisive minds have developed the reasoning-about-feeling project, as it might be called, in the intervening 250 years (Nussbaum, 2001). Nevertheless, it is clear that powerful and potentially destructive emotions remain widespread today from nationalism to group-think and greed as the primary foundations for collective and individual action. Without going into any detail, the continued pervasiveness of destructive emotions seems fairly evident as the underlying driving forces of the global financial crisis of 2008.

Reason and Unreason

Amartya Sen argues that “there is no irreducible conflict between reason and emotion” (2009, preface) in the sense that our feelings may contribute positively to our motivation and action. Just the same, reason was put into the driving seat with respect to defining justice in the political arena during the Enlightenment and thereafter. The real problem, as Sen so clearly points out, is the “prevalence of unreason in the world and the unrealism involved in assuming that the world will go in the way reason dictates” (Sen, 2009, p. xvii). While there was and is a well-informed and reasoned consensus that economic growth should be sustainable, events turned out to have been driven by exploitative and short-term motivation.

There is further cause to be skeptical about the easy march of social progress, whether in public health or other domains of collective action. There are at least two problematic aspects of the interface between reason and unreason. First, dogmas often ride on some kind of reasoning, such as self-interest. It is certainly possible to argue passionately for the status quo, despite a carefully documented injustice, with the support of elements of reason. Second, there exists the possibility that several positions may be “reasonable” with respect to a given injustice. For example, whether we tend to favor individual liberty or collective intervention, it is hard to deny that health inequalities are large and pervasive and, given the historically unprecedented level of global economic resources, such health inequalities could in principle be substantially erased. A pragmatic and reasonable objection is that our knowledge of the effectiveness of interventions to reduce health inequalities is far from complete. The decision to act in such circumstances of incomplete evidence thus depends on political values. Nevertheless, the difficulties with the way reason is used and the prevalence of unreason must not deter us from the use of reason in pursuit of justice, despite the skepticism we may feel.

Blueprint or Behavior?

We can measure unfairness with respect to the unequal distribution of health capability on many different social scales. Similarly, solutions can be conceived at different levels, depending on where the cause is seen to be located. One dichotomy is between institutions and people. Do we see the fundamental unfairness problem as one concerning the organization of institutions and systems of governance in need of reform, or alternatively as one about people and relationships? The answer is likely to depend on context, and involve both levels of explanation. Justice is considerably about people and how they are treated by those in authority, and how institutions function in respect of the diverse attributes of the population governed. This consideration is the foundation for arguing for the need for democratic institutions, but more than that, for institutions operated by people with democratic values. A vital question is whether minority voices can be heard, and whether they are heeded.

The dichotomy between these alternative points of focus, governance systems and people, may be helpful in developing strategies for public health progress. In *The Idea of Justice*, Sen highlights a related intellectual divergence (that may be traced back to Enlightenment thinking) which underlies his critique of John Rawls' conception of justice. Sen does not cut the pack of enlightenment thinkers along political lines. Under the heading *transcendental institutionalism* come Hobbes and Rousseau's hopes of social perfection pursued through a hypothetical social contract. In the avoidance of lives nasty, brutish, and short, there was seen to be a need to strive for institutions to match the ideals of justice rather than to focus on the behavior and interactions of people. This idealistic world view is contrasted with *realization-focused comparison* as practiced by Smith, Bentham, Marx, and Mill. These diverse thinkers are linked by their shared preoccupation with progress pursued through observation of manifest injustice, and by examining societies that already existed or might, to varying degrees, reasonably be expected to emerge.

John Rawls' 1970s Social Contract: Justice as Fairness

Given our concern with the socioeconomic gradient in health and social determinants of health, John Rawls as the best modern proponent of the social contract and ideal justice has much relevance. Rawls' difference principle has been dominant in thinking about the acceptability of economic inequalities in liberal societies over the past forty years. A central part of his argument, roughly stated, is that economic inequalities are acceptable from the perspective of justice as long as the increased inequalities work to the benefit of the worst off. The difference principle has two components: (1) equality in the assignment of basic rights and duties, embodied by impartial social institutions; (2a) all social and economic inequalities must be attached to positions that are open to all under conditions of equality of opportunity, and (2b) social and economic inequalities in wealth are just when they work to the benefit of the least advantaged.

This position is under intellectual pressure because there are reasonable questions arising out of real world events about the validity of Rawls' central conceptualization of what is a just society after the near collapse of the world banking system, and the staggering $14 trillion of state support that was needed to prop it up. The creation of some benefit to the worst-off may not be sufficient to conclude that justice is being done if the entire economic system is threatened by unbounded greed.

The difference principle indicates that there are both fair and unfair inequalities, based on the balance of likely positive and negative consequences for the society and social hierarchy in question. Well, the view of Adair Turner, chairman of U.K.'s regulator, the Financial Services Authority, was clear when interviewed in August 2009 (Ford, 2009). Turner supported the introduction of a global Tobin tax on financial transactions to curb profits and pay in the sector, and described some of the activity of investment bankers as "socially useless". On the other side of the Atlantic, Alan Greenspan, former chairman of the U.S. Federal Reserve, admitted to the House Committee on Oversight and Government Reform on 23 October 2008 that the "whole intellectual edifice" of the efficient market hypothesis collapsed that summer (Coll, 2009). On both sides of the Atlantic, Rawls' acceptance of socioeconomic inequalities in order to be aligned with the efficient market hypothesis and the central role of incentives for social progress has come under pressure.

Justice as Fairness: The Problems

Rawls' formulation of social justice based on fairness and the difference principle has to a large extent been seen as the ideal basis for social and economic arrangements, particularly since 1989 and the downfall of the Soviet system. Visible in the stark realities of the socioeconomic inequalities Rawls' thinking helped to justify before the onset of the present Great Depression, Rawls' central statements present two serious difficulties of interpretation:

- citizens will differ greatly in the weight given to equality (distributional justice) versus the compensating benefits of inequality (aggregate gain), and
- identifying just and fair institutional arrangements suffers from the indeterminate problem of defining what is and what is not feasible.

As a consequence of these two problems it is necessary, as Sen argues, to go beyond the focus on social rules to examine what actually emerges in terms of lives led. The implication of this line of thinking is clear. Rawls' view tends towards the idealistic stream of transcendental institutionalism in its heavy emphasis on the fair social contract and ideal institutions. Working to a blueprint has an arbitrary dimension, since other blueprints might do just as well or better, notwithstanding the fact that recent events suggest Rawls' formulation is flawed. Social progress may be better served by addressing injustices such as excessive economic inequality, and inequality in health capability, to the extent that real-world political constraints allow.

There is a hindsight perspective that adds another critical focus to Rawls' theory. His emphasis in relation to beneficial outcomes was on social goods. For example, Rawls was concerned with intangible assets such as self-respect as well as with material goods. Income and wealth were thus considered indices of social inequality that captured psychosocial aspects of disadvantage. Today, we have the novel insight that income inequality is an index of poorer aggregate health outcomes such as national life expectancy as well as progressively poorer physical health with lower social position (Wilkinson & Pickett, 2009). A contradiction therefore emerges, as it possible to justify an increase in income inequality in original Rawlsian terms, but if health outcomes are included among social goods, to find that the same increase in income inequality is unjust at both distributional and aggregate levels.

Sen's Capability Approach and Health

Going beyond equality under the law, and justice as fairness of social institutions, Sen emphasizes the value of freedom. Freedom allows us the opportunity to reason and to pursue both self-interest and wider objectives, including but not limited to health. This key aspect of justice is useful but also problematic, since defining freedom is a political and philosophical hot potato involving the broad concepts of control, choice, and power. Freedom is distinct from the utilitarian value of happiness and subjective well-being, which may be thought of as core health outcomes. Indeed these dimensions of human experience can be seen as the product of health capability of which freedom is a vital constituent. Because freedom has such a wide scope, including the potential to acquire great privilege, there remains a seemingly unresolved conflict between freedom and equality in Sen's thinking. At least on first approach, it is unclear how Sen's concern with individual freedom, seen as capability, reconciles the longstanding debate on the conflict and possible tradeoffs between liberty and equality.

Possessing freedom also means we can expect to be held accountable for what we do. While accountability fosters democracy and is intuitively desirable, by casting doubt on Rawls' emphasis on procedural fairness and instead giving weight to freedom, Sen provides only a loose guide to how the freedoms or liberties of powerful actors, such as investment bankers, are to be prevented from doing harm. Since it may be unjust for big fish to be able freely to devour entire shoals of small fish, there is a need to consider the nature of the status quo, not only its institutions and rules, but also its manifest harms. As outlined above, this consideration drives realization-focused comparisons applied to social inequalities.

Socioeconomic Inequalities in Health: The Disputed Ground

It is incontrovertible that relative inequalities in health outcomes continue, in general, to grow within and between countries. Taking a public-health focused view regarding health inequalities, Rawls' difference principle of social justice is probably breached. If the health inequalities gap continues to widen, whether as result of pulling away at the top of the hierarchy, falling back at the bottom, or some combination of both (but perhaps not if the health of the most disadvantaged continues to improve), then against the yardstick of Rawls' difference principle present levels of income and wealth inequality are not socially useful, and indeed are socially corrosive when other social outcomes such as social distrust, homicide, and imprisonment rates are brought into the picture (Wilkinson & Pickett, 2009). In Sen's terms, the liberties pursued by relatively privileged groups in the context of growing health inequalities may exceed their due social obligations, in violation of the freedoms and health capabilities of disadvantaged groups. With benefit of hindsight, it is hard to escape that conclusion with respect to what happened in the years before the recent financial crash, ensuing mega-bail-out, and the largely unreconstructed culture in the banking system today.

These objections to the present state of governance or status quo emerge from an emphasis on "health" or "health capability" as the key outcome of social justice. Clearly there are other domains of justice and freedom to be considered, possibly to be maximized along utilitarian lines. However, there is surely a strong case for placing health or well-being among the range of important social values such as national security and economic growth. This is not to argue for equal concern for citizens as being expressed through imposing equality in income and wealth, although such inequality has almost certainly gone too far for the greater proportion of the global population. Access to health care is an important institutional dimension of social justice for public health policy makers. The health care funding debate in the United States may have been unduly influenced by the unsustainable market-economic values of past decades. This problem is recognized in progressive initiatives that seek to counter the negative impacts of the idea that health is just like any other consumer commodity.

If redistribution in the domain of wealth and income is with the intention to increase social justice and reduce health inequalities within states or between states and global regions, there are at least three reasons why absolute equality of economic shares is a problematic political ideal. The first concern relates to *industriousness*. Why would we want a world where the lazy are rewarded with the produce of the industrious? The result of such a system is inevitably loss of incentive to work. The second concern is about the process of *equalizing down*. Almost everyone would lose, and the aggregate benefit of inequality would be lost. Nevertheless, partial redistribution to increase the health capability of disadvantaged groups is an expression of social solidarity and a successful political goal in many developed countries. The third concern relates to *diversity*. It can be argued that equality in shares of wealth and income is on the wrong side of showing equal concern for all citizens, who have wide variation in their needs and abilities. Inequalities in well-being and in other important dimensions will be generated by focusing purely on equality in the income-wealth domain.

Conclusions

Political philosophers have articulated the conflicts between freedom and solidarity, rights and responsibilities, individualism and conformity. Rawls' difference principle has been highly influential in policy thinking to reconcile these polarities with a liberal theory of distributive justice where, as well as there being a need for equality in the assignment of basic rights and duties, there is justification for social and economic inequalities in wealth and power, provided they result in benefits for the lesser advantaged, and in particular for the least advantaged. Sen questions the emphasis on this idealized social contract and recommends we pay closer attention to manifest social injustice and how we can address it. Two lines of evidence suggest there is a need to reconsider the present boundary between rights and responsibilities. First, health inequalities are growing, and such inequalities have their origins in social organization and values. Second, under existing social arrangements unregulated individual and corporate self-interest engendered the recent global financial crisis that threatened the health and well-being of us all, and particularly the least advantaged.

Public health values necessarily involve consideration of health inequalities and the consequences of acting, or not acting, to reduce them. Socially avoidable ill-health is a manifest injustice and those with effective power have the responsibility and obligation to act. Recent philosophical debates have addressed the "equality of what" question in a broad social justice framework. The insight helps us to appreciate that showing equal concern for all individuals means our attention should be distributed across three sites of action (1) health and well being itself, (2) personal and social resources, and (3) health capabilities – the conditions that affect health together with the ability to make informed health choices. Rather than being narrowly focused on distribution of healthcare or some conflict between individual liberty and the public's health, it is these areas of concern that should be the foundation of reasoning about public health morality and ethics.

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Solidarity in a Changing World

Martin McKee

Government as a Protector of the Individual

The creation of the modern European welfare state has been a remarkable achievement. Although taking many diverse forms in different countries, in all of them it has established mechanisms that protect the individual “from cradle to grave” by means of transfers from rich to poor, from those of working age to children and old people, and from those in good health to those who are ill (McKee, 2008).

The concept that individuals should care for those less fortunate than themselves long pre-dates the 20th century, with antecedents in all the major religions such as the Jewish *Tzedakah*, the Islamic *Zakat*, and the Christian giving of alms. However, the belief that the state per se should play a role in this process is more recent. Writing in the 17th century, the English philosopher Thomas Hobbes argued for protection by a strong government, in his case by an autocratic ruler, as otherwise individuals would live in what he described as the state of nature, in which “war of all against all” would lead to lives that were “solitary, poor, nasty, brutish, and short” (Hobbes & Gaskin, 1996). He envisaged a “social contract” whereby individuals would cede their individual rights for a guarantee of protection by a sovereign authority.

Hobbes’ desire for protection from threats to life was understandable given his experience of the overthrow of the established order, with its resulting violence and destruction during the English Civil War. However, his concept of a social contract has persisted, developing in ways that reflected changing views about the fundamental relationship between the individual and the state. These included John Locke’s model of a ruler acting as a “neutral judge” to protect the rights of individuals who have come together voluntarily for the common good (Locke & Goldie, 1994) and Jean-Jacques Rousseau’s idea of the “general will”; however, he had more faith than Hobbes in the ability of individuals to come together voluntarily, recognizing their self-interest in doing so (Rousseau & Gourevitch, 1997).

All of these writers did, however, have a limited view of the role of the state in protecting its citizens, covering only matters such as defense against attack by foreign armies or the upholding of property rights. Protection from poverty, hunger, and disease remained in the realm of charity, whether from individuals or through organized religion. It was only with the coming of the industrial revolution that the state began to play a formal role in these areas.

The Emergence of the Welfare State

The process of industrialization led to large numbers of rural dwellers flooding into the newly emerging industrial cities, often encountering scenes of appalling squalor (Engels & McLellan, 1993). The ruling classes had to act, although often more out of self-interest than altruism. One of their concerns was the fear of popular insurrection by discontented masses, which by now were concentrated in the cities and therefore more difficult to isolate. Their fears were stoked by Marx's warning of the specter of communism stalking Europe (Marx & Engels, 2004). However, change was also being forced by the re-emergence of a second specter, as cholera took advantage of the unsanitary conditions that prevailed (Porter, 1997). Something had to be done, and it was, with expansion of the franchise in many countries to include the male working class (in most countries women would have to wait another five decades or more to get the vote) and the emergence of the sanitary movement. Yet these measures did little to address the fundamental divisions within society, a situation described eloquently by the British Prime Minister Benjamin Disraeli as "Two nations between whom there is no intercourse and no sympathy; who are as ignorant of each other's habits, thoughts, and feelings, as if they were dwellers in different zones, or inhabitants of different planets. The rich and the poor" (Disraeli & Smith, 2008). It was only at the end of the nineteenth century that the basis of the modern European welfare state did begin to emerge, exemplified by the creation of sickness funds in Bismarck's Germany, but these, and their counterparts in neighboring countries, remained limited, typically including only those working in industry and their families (Saltman & Dubois, 2004). It would take many more years for universal systems to be established.

Yet, for the present purposes, what is important is that these systems have been established. All European countries now have well-established systems that, while undergoing periodic reforms, have not departed from the fundamental principle of universal coverage. In the health care arena, no one in Europe need now fear financial ruin as a consequence of catastrophic illness, nor need citizens of most other advanced industrial countries, such as Israel, Canada, Japan, or Australia. The rationale, to most Europeans, is obvious. Those who are most in need of health care are often those least able to pay.

American Exceptionalism

The stark exception to this model is the United States. Alone among industrialized countries, despite its great wealth, its expenditure of 15% of that wealth on health care (World Health Organization, 2009), and its achievements in so many other areas, it has singularly failed to provide health coverage for its population. In excess of 40 million Americans are now uninsured, while even those with insurance often face exclusions and high levels of individual contributions that leave them vulnerable in the face of ill health. Unsurprisingly, medical bills account for more than half of all personal bankruptcies in the United States (Himmelstein, Thorne, Warren, & Woolhandler, 2009), while deaths that are preventable remain at higher rates than in other industrialized countries and are declining at a much slower rate than elsewhere (Nolte & McKee, 2008). This is a situation that, at least to European eyes, seems bizarre. Surely the American people would look to what exists in Europe and seek to emulate it. After all, adoption of the principles underpinning the European welfare state would, overall, substantially reduce the cost of health care, would improve access to care, and would improve the outcomes of that care. Yet, remarkably, this is not the case. President Obama, who was elected on a manifesto that included reform of the American health care system, now faces widespread opposition to a measure that will benefit most Americans. To an outsider, it is less the scale of the demonstrations that is shocking, taking into account the way that media outlets such as Fox News have exaggerated their magnitude (it showed footage of an anti-Obama rally that purported to have taken place in November but, as a rival network Comedy Central noted, the clear skies and leaves on trees gave away that it had taken place months earlier) and their shameless misrepresentations of

European health systems. Rather it is the venom of some of those protesting, whose placards conflate images of Obama with those of Hitler, and his policies with those of the Nazis. How is it that, as a growing number of American political commentators have noted (Frank, 2004), large numbers of their compatriots are now voting against their own self-interest? This question is important for America but also, I shall argue, for Europe as it looks to the future of its own welfare models.

The evidence of American exceptionalism (Lipset, 1996) in social policy is apparent in many ways. The United States spends less on social and family benefits than any other major industrialized country. Thus, although its poverty rate is in line with elsewhere before social transfers, once income has been redistributed through taxes and benefits, on a lower scale than in other countries, its citizens are much more likely to live in poverty. These outcomes reflect deeply seated views among the American public. Many Americans still see their country as a land of opportunity, with 71% believing that the poor can escape from poverty compared with 41% of Europeans, even though, in reality, poor Europeans are much more likely than poor Americans to do so (Alesina, Glaeser, & Sacerdote, 2001). There is also a longstanding suspicion of government, apparent in the recent rise of the Tea Party movement, named to commemorate the Boston Tea Party in which American colonists protested against British taxes on tea in the run up to the American War of Independence. It is also apparent in responses to natural disasters, exemplified by the American commentator on a BBC news website who, despite the overwhelming dominance of poor African-Americans in the scenes of devastation following Hurricane Katrina, called for “Shame on anyone that makes this tragedy political, socio-economic or racial. ... in the land of opportunity and personal responsibility the individual is ultimately accountable” (Wells, 2005). Similar views have recently been expressed in response to the 2010 Haitian earthquake, with media commentators calling on Americans not to donate money for relief lest the federal government steal it. Fortunately, such views, while vocal, are not universal, with Nobel Laureate Paul Krugman also observing with respect to Hurricane Katrina, “... the federal government’s lethal ineptitude wasn’t just a consequence of Mr. Bush’s personal inadequacy; it was a consequence of ideological hostility to the very idea of using government to serve the public good. For 25 years the right has been denigrating the public sector, telling us that government is always the problem, not the solution. Why should we be surprised that when we needed a government solution, it wasn't forthcoming?" (Krugman, 2005).

Although the United States does seem to be a clear outlier in terms of solidarity, it is important to recognize that the European welfare state does not take one distinct form. In fact, there is great diversity, with differing roles played by governments (central and local), employers associations, and trade unions. These various forms achieve different results, as seen in a recent study comparing the probability that unemployed people will be in worse health than those who are employed, in different versions of the welfare state (Bambra & Eikemo, 2009). The unemployed, both male and female, do worst in the relatively ungenerous Anglo-Saxon model, such as is seen in the United Kingdom, and best in Southern Europe, where the welfare state is complemented by extensive systems of family support. Unemployed men fare less well in Bismarckian systems that emphasize the role of the male breadwinner, while women do less well in Scandinavian systems where they may have accumulated fewer benefits through more time spent in working part-time. Nor have the European systems eliminated social inequalities, with the recent report of the Commission on Social Determinants of Health highlighting very wide disparities in life expectancy within a single European city-Glasgow (Marmot, 2008). Yet at least all European countries are trying to address these problems. Why is the United States so different?

A number of explanations have been proposed. One is the nature of migration to the United States. Elazar has described three political cultures, reflecting the dominant origin of migrants to different parts of the country (Elazar, 1972). Puritans and Scandinavians (designated as moralist), with traditions of social justice, moved to northern New England. Scots-Irish and Germans (individualist), who emphasized individualism, settled in Pennsylvania and New Jersey. Finally, a slave-owning elite (traditionalist) settled in the southern states. In each case, subsequent waves of westward migration replicated this division. Recent work has shown how this political culture has persisted, influencing rates of avoidable mortality among African Americans, many of whom depend on state-determined policies on Medicaid eligibility (Kunitz, McKee, & Nolte, submitted).

Another characteristic that distinguishes the United States is the absence of a socialist party. The reasons are contested but some factors may be relevant (Lipset & Marks, 2000). One is geography, with the dispersal of population over large areas inhibiting communication among the working class. Another is the political structure that creates a powerful barrier to parties other than the Republicans and Democrats (Alesina et al., 2001).

Race: The Elephant in the Room

There is, however, a third factor that is less frequently discussed. This elephant in the room is race. There is now compelling evidence that attitudes to welfare are shaped by racial context (Alesina & Glaeser, 2004). Thus, support for welfare is greater among people who live near many welfare recipients of the same race, but lower among people who live near welfare recipients of another race. Support for welfare is greatest among whites who answer positively to the question "Have you had a black person for dinner in your home in the last few years?" (Luttmer, 2001). This is also seen at the state level. Those states with the highest proportion of the population that is African-American provide the least generous welfare regimes, a picture that is also seen globally, in research correlating social welfare spending with racial fractionalization (a measure of national diversity) (Alesina & Glaeser, 2004). This then raises a question that is fundamental in any consideration of solidarity: Solidarity among whom? Who are we (the community that we identify and with whom we agree to share resources)? And, by extension, who are we not?

A Veil of Ignorance

The European welfare state has many of the features set out by John Rawls in his theory of justice (Rawls, 1973). He argued that, in determining policies, citizens' representatives should be placed behind a "veil of ignorance" that would prevent them from knowing who they are representing. In such circumstances, they will adopt the "maximin" position, making the choice that produces the greatest payoff for the least advantaged as they must assume that this is the group that they do, in fact, represent. This is essentially the situation that pertained in Europe during World War II, in which even the wealthiest individuals had been forced to come to terms with the fact that overnight they could lose all they possessed. This applied to everyone, regardless of whether they were on the “winning” or “losing” side (Gilbert, 1986; MacDonogh, 2007). As a consequence, that generation put in place systems of social solidarity that would look after them wherever they might end up in an uncertain future (as well as systems, such as the European Economic Community, that reduced the risk that such misfortune would ever return). Similar sentiments were apparent in Israel, with the creation of communal institutions through the Kibbutz movement. The situation in the United States was, however, very different. While a European caught up in a disaster might go to bed rich but wake up poor, a white American was safe in the knowledge that they would never wake up black.

This has important implications for Europe in the years ahead. The Europe of 1945 was a racially homogeneous society. The Europe of today is not, and is becoming increasingly less so. Europe, with its aging population, needs migrants – as workers, taxpayers, and carers. Yet it has not always seemed to accept this need. Especially in areas where there has been large scale migration and where low educational attainment among the indigenous population, combined with de-industrialization, has reduced employment opportunities, there has been growing evidence of racial intolerance. In several countries, political parties standing on an explicitly racist platform have succeeded in elections. In some cases, these parties wear emblems that bear more than a passing resemblance to the Nazi swastika.

At the same time, solidarity is coming under pressure from a different direction. The ageing population that has played a part in migration is also creating its own divisions in society. Some politicians are presenting elderly people as a burden on society, asking why the young should pay for pensions and the health and social care that are needed by older generations. So far, inter-generational solidarity remains strong in Europe, not least because most people do recognize that they too will one day be old (Doyle, McKee, Rechel, & Grundy, 2009). Yet as the experience of the United States shows, concerted political campaigns supported by populist media commentators can create a situation where large numbers of people vote against their own self-interest.

The Future?

Paradoxically, given how the New Deal emerged from the Great Depression of the 1920s and 1930s, the current economic situation may put additional pressure on the European commitment to social solidarity. Naomi Klein has described in detail how neo-liberal politicians and their corporate supporters have been exploiting disasters, both natural and man-made, to pursue their own interests, with especially egregious examples including Hurricane Katrina and the 2004 Asian tsunami (Klein, 2007). This is already apparent in calls by some politicians in the United Kingdom, which has long occupied a mid-Atlantic position on solidarity, for deep cuts in the welfare state that they portray as unaffordable, basing their analyses on misleading statistics and a rejection of empirical evidence (Brittan, 2009).

So far, the principles of the welfare state have endured in Europe and in Israel. The concept of social solidarity remains strong. A recent survey found that most Israelis were surprised by the extent of inequality in Israeli society and supported a greater political priority for policies to address it (Epstein, Goldwag, Isma'il, Greenstein, & Rosen, 2006). Similar sentiments are apparent across Europe. Yet, the American experience should be a warning. Support for solidarity in a changing world cannot be taken for granted.

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Legends of Health Policy and Management

David Chinitz

> “I am attracted to economics as a branch of philosophy and as a house of study in which there takes place, or at least could take place, a reasoned discourse regarding social arrangements.”
>
> Ariel Rubinstein (Legends of Economics, 2009)

Introduction

Public policy analysis was born of the desire to increase the rationality of large public programs, taking its lead from systems analysis as applied in military contexts (Radin, 2000). As the field developed, the emphasis on technical, mostly quantitative, tools of analysis was supplemented with sensitivity to politics and social context (Bardach, 2005; Wildavsky, 1979). Special attention was devoted to policy implementation (Bardach, 1977; Mazmanian & Sabatier, 1981). Policy analysis had begun to supplement the “legends” at its roots, namely, that quantitative modeling could dominate policy making, with the insight that politics would need to be taken into account.

Nonetheless, the desire to “depoliticize” policy replays itself, to quote the Passover *Haggadah*, “in every generation”. New Public Management sought to replace the vagaries of public administration with clearly defined contracts between the public and private sectors. Needless to say, governments discovered that contracting for social goods is far from straightforward, and that not everything of value can be captured, a priori, in a defined “bottom line” that contractors are to be measured by (Cohen & Eimicke, 1998). Social arrangements and the human interactions they structure can be framed by quantifiable goals up to a point. Accountability for results is dependent not only on pre-determining desired end points, but also on negotiation regarding the interpretation of results and the rewards or sanctions that should follow.

A good example is provided by Hirschman's concepts of *Exit, Voice and Loyalty* (1970). Exit, based on the economic notion of a free market, is linked closely to signals, such as prices, that enable consumers to move between suppliers, and is a relatively clear mechanism of accountability. But Hirschman explains why exclusive reliance on exit may be suboptimal, and resort to voice and loyalty may be more effective and more efficient. However, it becomes readily apparent that voice and loyalty are much more difficult to model quantitatively than exit. The study of the former two requires, among others, qualitative tools of analysis to capture the processes and results of social arrangements that are not markets. And, of course, economists themselves, especially those with an institutional orientation, also see the need to supplement market models with systematic analysis of non-market arrangements such as firms, collectives, and bureaucracies

The ability to combine hard, quantitative analysis with soft, qualitative analysis is an ongoing challenge. While the term socio-technical was coined decades ago, it seems that every new policy challenge is first looked at through quantitative models, and attention to the "socio" is secondary and even residual. This is acceptable, as long as it is carried out in a self-conscious way, and that eventually the political, social, and ethical aspects of policy are sure to have their day. The danger is an overwhelming focus on the quantifiable "hard" models that encourages obliviousness to the qualitative "soft" variables that also require attention.

Health policy and management have been dominated by hard, mostly economic, models during the last three decades of health reform in Western countries. The reasons for this go even beyond the above described cognitive tendency to prefer quantitative analysis. In health care, tough ethical dimensions of resource allocation, connected to perceptions that the field deals with matters of life and death, increase even more the desire to "escape" towards the technical at the expense of the social. However, the experience with technically based health policy interventions has laid bare the need to address, with political and social tools, those aspects of health systems that cannot be addressed in a politically neutral manner. So, for example, in both Israel and the United Kingdom, introduction of internal or regulated health markets led, almost inevitably, to the creation of bodies charged with ranking new health technologies - NICE in the United Kingdom, and the Committee to Update the Health Basket of Services in Israel. The highly charged debate over health finance has led to an increased focus on health inequalities and prevention, with the value laden considerations that accompany them.

Given this background, this paper first describes the "legends" that have been created around health policy and management resulting from the desire to "escape" into the realm of technical models. Following that, a number of "new" legends are proposed that seek to achieve a better mix of technical and social models for health and health care policy. Some empirical data are reported as illustrations of how technical and social models can complement each other. Finally, recommendations for health policy analysis in the future are proposed.

Legends We Live with

"Money talks": Economic incentives reign supreme

Historically, physicians were paid in one of two ways: fee for service or salary, depending on the type of health system in which they worked. Beveridge-type systems favored salary, and insurance-based systems fee for service. In some systems, notably the British and Israeli cases, community-based physicians received, from early on in the twentieth century, some form of capitation payment, but these were often blended with salary and seen as such. Provider organizations, such as hospitals, also received either fee for service or prospective budgets.

With the rise of cost consciousness in health systems, analysts began to examine the "incentives" pertaining to these reimbursement mechanisms (Rosen, 1989). Fee for service was readily linked to supplier-induced demand, while salaries and prospective budgets were thought to induce malingering, leading to unresponsive and inexpeditious services.

Enter capitation and differential payment schemes, such as Diagnosis Related Groups (DRG). The former would limit moral hazard, the latter would induce efficiency. It would be difficult to argue with the widespread adoption and impact of such reimbursement mechanisms (Scheller-Kreinsen, Geissler, & Busse, 2009). However, much less attention has been given to the context in which they are implemented. DRGs in the U.S. Medicare program were accompanied by mechanisms, such as Peer Review Organizations, to limit the incentive to increase volume.

DRGs in European systems were introduced within capped budgets. Capitation payments work differently when given to physicians working in Independent Physician Associations than in the context of pre-paid group practices.

The challenge of considering the payment mechanism within its organization structure context, while not totally ignored in the literature, has been a relatively undeveloped field. Recent discussions of Pay for Performance (P4P), while focusing on how to measure performance, tend to pay less attention to organizational context, cultural influences, and values.

There is a need to supplement the quantitative impacts of financial incentives with consideration of the broader social context in which they are deployed.

"This is Israel, not Finland" - Culture, norms, and values are out of our reach

The importance of cultural context has not escaped notice in the literature on comparative health systems. Nonetheless, the health policy literature is long on what Bardach (2005) calls "best practices research, and short on what he calls "smart practices research". The best practice approach looks for successes that have taken place abroad, and too rapidly assumes that success can be replicated at home. Smart practices is more subtle; it takes into account special factors surrounding the implementation success story, and asks not only about the specific policy intervention, but also what environmental parameters contributed to success. Indeed, I would argue that what has failed elsewhere might be worth considering at home, if contextual reasons for failure elsewhere do not obtain at home. But the story doesn't end there.

"Trust me, I'm a doctor" - culture isn't affected by technical interventions

The problems go beyond taking things out of context. There is also the tendency to take culture, norms, and values as givens. In reality these contextual parameters may not only inhibit or enhance a given technical policy initiative, but may also be influenced by the policy process. As Oliver Williamson (1975, 1996) has pointed out, the micro-analysis of transactions, using economic and game theoretic tools to predict the level of transaction costs involved, must take into account "atmosphere", i.e., cultural tendencies. Where opportunistic behavior is the cultural norm, various kinds of contracting may fail more readily than in societies where individuals tend to act more in good faith. On the other hand, introducing transactional tools such as contracts, measurable bottom lines, financial incentives, and the like, may eat away at trust between actors and produce counter-productive results.

The importance of culture and how it reacts symbiotically with technical policy interventions requires more attention than it has been give to date.

"The numbers don't lie" - measurement is not subject to opportunism

Much of policy analysis, especially as it has taken the form of the New Public Management approach, is based on the understandable desire for a clear bottom line, a measure of performance not subject to controversy that can be used to hold actors to account. One not need look much further than the fate of hospital "report cards" in the United States (Werner & Asch, 2005) to find difficult issues over assigning responsibility in instances of medical errors or damage to patients, and discussions of "patient responsibility" to know that such exact bottom lines are not readily available (Chinitz, 2007; Hoffmann & Perry 2005; Merry & McCall-Smith 2001). This does not imply abandonment of the search for better measures of performance, it just suggests that whatever measures we have will be subject to gaming and interplay among various actors in the health system.

We need to look systematically at these interactions and consider institutional frameworks for mediating them that will improve accountability rather than leading to undue tension among actors in the health system.

"We had it right, but the politicians got in the way" - health needs to be depoliticized

Accountability in politics is perennially elusive, but in health policy even more so. Politicians are loathe, as would anybody, to take responsibility for decisions that appear to deal with "life and death". Reorganizations in health systems have appeared to be driven by the desire to reallocate or, more appropriately, pass on to somebody else, accountability for tough decisions. Decentralization is often justified in the name of efficiency, but also carries with it responsibility for allocating scarce health resources to competing needs and wants to which the public is sensitive (Saltman, Bankauskaite, & Vrangbeck, 2007). In Israel, the process of updating the basket of health services provided under national health insurance has often found its way to the desk of the prime minister, with the usual result that funds are added to assuage public pressure over lack of funding for high profile "life saving" drugs. In Britain, the National Institute for Clinical Excellence makes recommendations regarding inclusion of new drugs and treatments in National Health Service coverage. These recommendations are supposed to be apolitical. But the financial decisions involved in adhering to these high profile recommendations falls to Primary Care Trusts working within a capped budget. Decisions on whether to increase the health budget or leave the tough decisions to lower levels are political (Eddama and Coast 2009). U.S. President Obama and his administration speak about "cost effectiveness" research as if it is solely a technical exercise devoid of political input. But while politicians may be ostensibly removed from the actual allocation decisions, they are responsible for the mechanisms that make them. We need the ability to create institutions that can meld scientific and political accountability for rationing health care.

"I'm here to spread the wealth" – health inequalities have to wait for social inequalities

There is extensive literature demonstrating the dependence of health status on socioeconomic status and disparities in income and education in society (Epstein, 2006; Evans, Barer, & Marmor, 1994; Marmot 2001). Public health proponents have, for a long time, decried the disproportionate resources allocated to curative health care and argued that the real causes of illness and disease lay in basic social conditions such as housing, education, sanitation, and environment. But, linking back to the previous point regarding politics, it is not enough to base this argument on epidemiological evidence, when the politics of health revolves, in part because of public concerns and provider incentives, around curative health services. The well known World Health Organization definition of health: a state of complete physical, mental, and social wellbeing, almost automatically pushes health ministries into the bailiwicks of every other government ministry. The latter have their own interests and goals, which may or may not coincide with promoting public health. Ministries of transportation have a clear incentive to build roads, which may have mixed, at best, outcomes for health. The first step towards redressing health inequalities may have to come from within the health system itself. By moving within the health system from an overwhelming focus on health care to a focus on promotion and prevention, perhaps the health system can take the first steps towards closing overall social gaps, as opposed to waiting for change to come from outside the health system. The politics of health care, as discussed in the previous point, has lead to some increased discussion of the role of health promotion and prevention as tools for achieving efficiencies in health insurance arrangements. We need to explore and firm up the links between health care politics and the politics of public health.

Creating New Legends for Our Own Time

All of the above points lead to the need for a reconfiguration of the relationship between health policy analysis as it has been practiced in its most technical, quantitative form, and the softer realms of social support that are required to further advance health policy. We can choose to live with our current legends, or we can seek guidance from contingent fields that, while not as quantitatively structured and "neutral" in appearance as, say, financial incentives subject to regulation, have the potential to structure our attention to the elements left out of our existing legends.

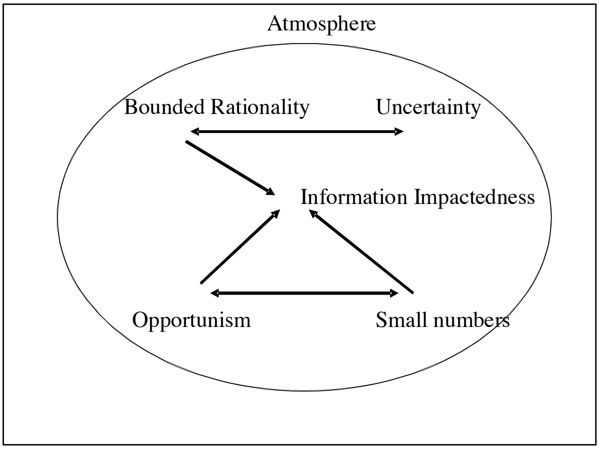
Four schools of thought come immediately to mind:

- Institutional economics, represented by scholars such as Douglass North (1990) and Elinor Ostrom (1990), encourages us to focus on social support mechanisms that can enable institutions that, according to economic and game theoretic models, have no self-correcting mechanism. Public understanding of difficult policy decisions, and public trust in institutions that make them, can defuse the political "weight" of decisions regarding allocation of health resources. Consensus, based on cultural norms, regarding values, trust, and social cohesiveness can help to overcome market and organizational failures predicted by strict economic analysis. These resources of political and social capital, trust in institutions, and trust in society, should be exploited in designing options for health policy.

- Behavioral economics, represented first and foremost by Twersky, Kahanneman, and Slovic (1980), teaches us that models of behavior based on assumptions of rationality need to be reconsidered in light of actual revealed preferences. Data on performance of hospitals has shown to have little effect on decisions of patients, physicians, and insurers when deciding where to seek care (Bevan, 2008; Werner & Asch, 2005). Anecdotal evidence indicates that not all physicians in Jerusalem react similarly to the incentive provided by the opportunity for private practice in public hospitals. Some physicians, in contraindication to economic models, forego provision of private service. Enriching our simulations of how various policy interventions will work in practice, by taking into account unexpected behavioral responses, can widen our options and improve policy management.

- Transaction cost economics, the school most closely associated with Oliver Williamson, is best known for the attempt to rigorously model the impact of alternative institutional arrangements on the smoothness with which economic transactions are carried out. Both markets and hierarchies have points of weakness when it comes to the relative ease with which actors can complete exchanges (Williamson, 1975, 1996). This school provides us with tools to examine, for example, how various financial incentives will influence behavior of health providers. If outcomes are easily measured, market type incentives, combined with accepted measures of performance will work relatively well. However, if information is unevenly spread among parties to transactions, then both markets and hierarchies are challenged. This calculus is neatly portrayed in the inside portion of the following figure.

Figure 1: *Organization failures framework (Williamson, 1975).*



While not necessarily captured by quantitative analysis, factors such as the level of uncertainty faced by actors, as well as their tendency to fall victim to limited cognitive capacities (bounded rationality) or to act with guile (opportunism), can be analyzed systematically. Such "comparative institutional analysis" can be used to adjust the institutional framework to minimize these sources of transaction costs. Of equal importance, but receiving far less attention, even by Williamson himself, is the "outside" realm of "atmosphere", namely, factors such as culture, norms, and values that not only influence the behavior of actors as they "play" within the inner circle, but also are affected, as alluded to above, by the carrying out of transactions within whatever institutional framework has been chosen to organize a given activity. Thus, the introduction of market mechanism, for instance in the famous case of blood donations analyzed by Titmuss (1970), led to the perverse result of a reduction in the supply of quality blood contributions.

- Organizational theory and management constitutes a huge literature. Within the vast array of perspectives on these subjects, two schools of decision making, strategy, and behavior stand out: the rationalist school and the incremental school. These parallel the concern in this paper with meshing technical and social systems of policy making. The first school extends theories of individual rationality to the behavior of organizations, almost as if the latter had the same type of volition and cognition as individuals. The incremental school, on the other hand, sees organizational behavior more as the accumulated result of the interaction of subsystems within the organization. A leading proponent of this view, Henry Mintzberg (1989), views organizational decision making and strategy as emerging from the history, configuration, and experience belonging to an organization. The role of the manager or leader is not so much to bring exogenous strategies to the organization, but rather to mold strategy based on the "received wisdom" of the organization.

In health care much has been written in recent years about "evidence-based medicine". This rationalist approach uses the tools of epidemiology and statistics, for example in randomized clinical trials, to try to reduce uncertainty regarding "what care is actually of value". Perhaps too rapidly, the next motto has been "evidence-based management", in the sense of also looking, in the spirit of "best practices research", horizontally from one system to another to see what works. But evidence-based management, looked at through the incremental approach, supplements the horizontal search for solutions with a vertical exploration within the organization. What will work in one context will not necessarily work in another, in the spirit of "smart practices research" alluded to above. We can systematically combine the horizontal and vertical in assembling the evidence base for policy and management decisions. As opposed to the optimizing spirit of evidence-based medicine, evidence-based management echoes the contingency approach, namely, there is no one right way to organize, and all technical solutions must be adapted to the contingencies of the specific organizational setting.

Legends for Our Own Time

A renewed, and recalibrated, conceptual approach, based on a measure of "affirmative action" for social and contextual considerations, is now on the table. Beyond improvement of health care policy, increased attention to social support, underpinned by the perspectives discussed in the previous section, would appear to be conducive to tackling issues of health inequalities and public health concerns, such as prevention and healthy lifestyle. Some new legends of health policy and management are suggested:

- The desire to remove politics from health policy, and the tendency to view politics as the obstacle to evidence-based decision making, has been discussed above. Many have labeled this the technocratic wish (Chinitz, 1999). A more realistic view is that politics is not only an unavoidable and legitimate part of decision making regarding the allocation of health resources, but also that evidence-based medicine itself is a political endeavor. As was made clear in recent debates about mammography and the etiology of cancer (Partridge & Winer, 2009), experts are often in disagreement. The politics of science is no less salient than the politics of fiscal policy. Confronted with health politics, pluralistic democracies have often evinced a "democratic wish" (Morone, 1990); namely, the desire for policy to be grounded in the "voice of the people". A whole literature has developed that combines these two wishes, that which examines what might be called the "technocracy of participation", an attempt to optimize public input into policy making (O'Dowd, 2010). In a system with adequate social support, policy making could be seen as legitimate, despite fulfilling neither wish, if it were a coherent, if not completely rational or consistent, blend of both. Health technology assessment and citizen input are both important inputs to decision making. There is no gold standard for combining them. However, the symbiosis between them, for example, two-way lines of ongoing communication between bodies such as NICE, and public views as captured by surveys and deliberations, can provide the social support necessary for making difficult, but unavoidable, health resource allocation decisions. As an example, Daniels and Sabin (2008) have proposed a framework called "Accountability for Reasonableness" (AFR). AFR requires that health resource allocation decisions be rational, transparent, and subject to appeal. The point here, however, is that AFR, while well defined, is not an exact science, and that the particular mix of its three components that will suffice for a given health system will be a function of levels of public understanding, trust, and ongoing public discussion; namely, what we have labeled here: social support.

- Getting Agencies to Work Together. While mechanisms such as capitation and global budgets are appropriate for well-defined bundles of care, interdisciplinary and cross-sector realms such as mental health and health education require more systemic bundling. This has been known for some time, but few systematic attacks on the challenge of inter-agency cooperation have emerged. An exception is *Getting Agencies to Work Together*, by Eugene Bardach (1998), which discusses the "craftsmanship" of cross-sector work. Entrepreneurial behavior and purposefulness are to be found in government and public sector settings, and societies engage in suboptimal behavior when they seek to empty these out in favor of contracting with the private sector. Systematically mapping the needs for cross-sector work, identifying the willing stakeholders and creating frameworks to allow them to act is the way to go in making a concerted attempt to encourage public health initiatives such as healthy lifestyle and reduction of health inequalities.

- Quantitative and Qualitative data, separately, but more importantly, together, have a role. Too often, qualitative research is seen as only a prelude to "real" quantitative research. But if we are to get, as an example alluded to above, financial incentives to work without undesirable side effects, or with a minimum of intrusive regulation and monitoring, we would do well to more systematically understand how such incentives are understood and acted on by providers. This means that quantitative measures of outcomes of policy interventions should be supplemented with qualitative exploration of how they are carried out. The interactions between quantitative management, say of clearly measurable bottom lines, with qualitative management of tradeoffs between autonomy on one hand, and the drive to meet externally set targets on the other, must be constantly monitored. Both summative and formative content and process evaluation are needed.

- Public understanding and support can be encouraged by improved public discussion of policy processes and outcomes. Following from the previous point, measures of outcomes, processes, attitudes, and preferences should not only be collected, but routinely fed back into public debate. Decision makers should be aware of public opinion on issues such as the allocation of health resources. The public should be polled as to its knowledge and awareness of policy processes. But

> it should not stop there. Inconsistencies in public attitudes and divergences between evidence-based practice and public preferences should be presented to the public for their reaction. This is part of an ongoing process of public debate, which provides support to decision makers to behave responsibly and be held accountable.

Where's the Beef? Evidence for Social Support

The argument of this paper is that technical solutions to health policy problems have avoided a conscious and systematic addressing of the social context in which policy is made and implemented. Policy solutions are meant to be technical, indeed, in order to avoid the soft underbelly of conflicts over "values", which are assumed to be intractable (Chinitz, 1999; Morone, 1990). Social support is difficult to measure, let alone influence.

In this section we present examples of results from a number of research projects that have sought to check, among other things, the degree of social support for health policy making in Israel. Note that this is distinct from public support for specific policies. Without going into the entire methodology, which has been described elsewhere (Chinitz, Meislin, & Grau, 2009), rather than ask respondents whether they favor particular policy decisions, we ask questions regarding their basic knowledge, attitudes, values, and perspectives. We suppose that these are influenced by policy decisions and public debate. We view these data as part of a discussion with the public rather than a one-off "take away message" for decision makers.

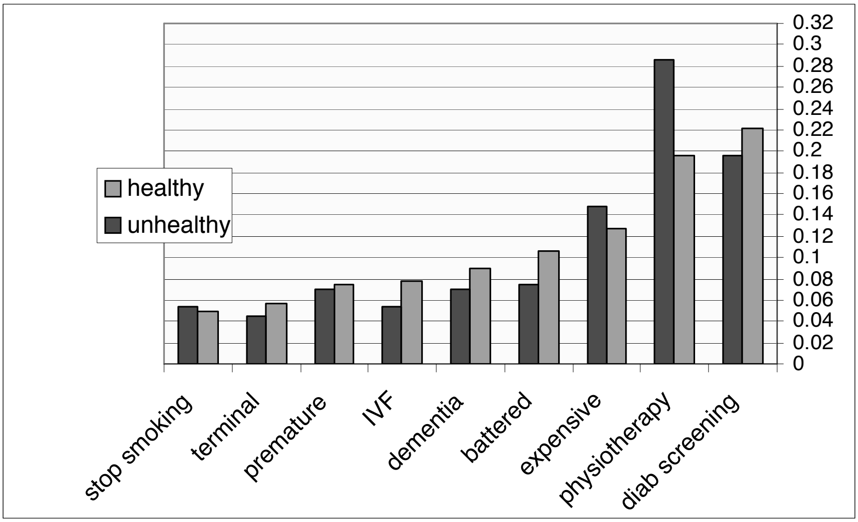
A striking, and perhaps unexpected, finding concerns public views on criteria that should be used in deciding whether new drugs should be added to the standard basket of health services provided under National Health Insurance. High levels of importance for evidence of effectiveness and contribution to quality of life are indicated in Figure 2. This is important, and likely unknown, to decision makers who might assume that the public is most concerned with life saving at any cost.

Figure 2: *View of the Israeli public regarding criteria for evaluating medical technologies.*

	% attributing high importance	**% attributing high importance**
	2004	2008
Evidence	77	66
Cost to Government	48	64
Cost to Individual	70	65
Number treated	65	62
Quality of life	80	70
Years of life added	72	38

Related to the above finding are data showing that the Israeli public gives relatively high priority to preventive interventions, as can be seen in Figure 3. However, it is also true that the public gives relatively low preference to behavioral preventive interventions, as opposed to medical ones such as screening and preventive therapies. However, combining the two findings, the implication would be that structuring public discussions in which the effectiveness of behavioral interventions could be highlighted might be worthy of consideration.

Figure 3: Relative preference of the Israeli population for preventive interventions, 2008.



Numbers on vertical access indicate likelihood of choice in any paired comparison.

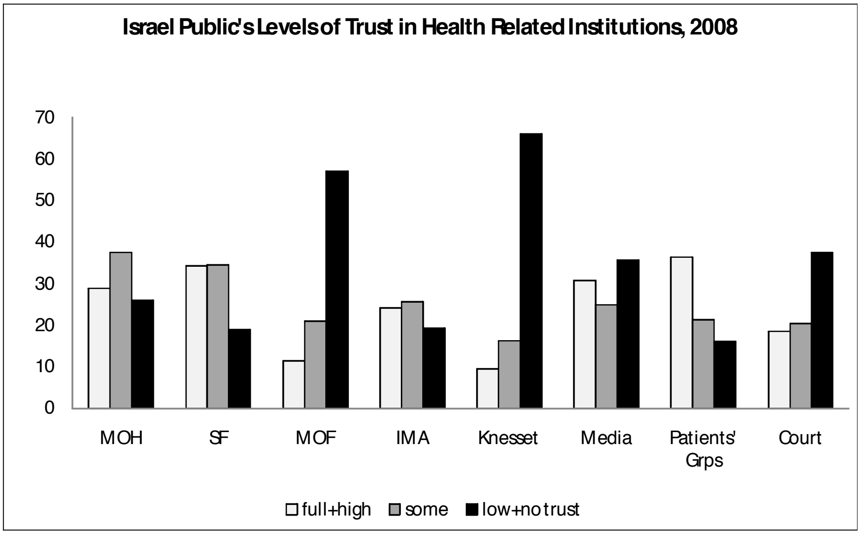
Another issue facing the Israeli health system is inequality. As can be seen in Figure 4, the Israeli public is not only aware of disparities in access to health care, but favors steps to reduce these inequalities. On the other hand, the public is less favorable to redistributive policies, such as higher taxes or transfer of budgets from better off to less well off regions. In this case, we argue that such data, with its contradictory results, should serve as the basis for a discussion and not as closing the door on redistributive policies. Decision makers should enable the confronting of the public with the data, in order to see what, if anything, changes: the desire to close gaps, or the relative lack of willingness to pay.

Figure 4: *Israeli public's agreement with statements about health inequalities, by language of questionnaire (%), 2008.*

	Hebrew	Arabic	Russian
Everyone can get health services when needed	68	92	62
Health services available easily in reasonable time	61	81	44
Equal attitude of doctors towards patients	41	76	54
Health=basic social right	92	96	87
Actual health basket matches or more social right	43	61	43
Increase health budget to periphery to reduce health inequalities	79	85	74
Higher taxes to reduce health inequalities	38	48	5
Transfer health budget from center to periphery	47	67	40

Social support includes the degree of trust that the public has in the policy making machinery. Widespread low and declining levels of trust in government have been documented in many countries, particularly the United States and Israel (Epstein, 1998; Healy, 2009; Israel Democracy Institute, 2009). Therefore, in the face of a presumed skeptical atmosphere, it is perhaps heartening to note the relatively high levels of trust that Israelis place in the main institutions dealing with health policy, the Ministry of Health and the Sickness Funds. Connecting this with the previous data on inequalities, one can assume that members of sickness funds that have initiated their own programs to reduce inequalities of access and health outcomes, would benefit from and contribute to social support in the health system.

Figure 5: Israeli public's levels of trust in health related institutions, 2008.



Conclusion: "If You Will It, It Is No Dream"

This paper has argued that a more systematic approach to integrating issues of social support into health policy analysis is needed. Reviewing the state of the art of "technical" analysis, which we have argued has dominated policy and health reform debates in many countries, we identify additional approaches that have potential to round out technical approaches with social sensitivity, avoid disruption of social solidarity caused by aggressive implementation of technical reforms, and enhance the success of policy implementation by taking advantage of available social support. Thus, we propose that the way forward involves continuing to refine our technical tools, while focusing on social support so that we can implement health policy that is both responsible and accountable.

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Social Support, Health Promotion, and the Built Environment: Vignettes from the Active Living by Design Program

Lawrence Brown

Introduction

Health policy debates in the United States are too often framed around a dichotomy between public and private sectors and forces. Historically this dualism is misleading, for a third sector-voluntary institutions, though often lost from view today, were enormously important in shaping the health care system's institutional arrangements, which bear deep traces of their origins to the present day. The system's famously "private" health insurers - notably Blue Cross - were originally advertised as embodying the special virtues of their progenitors, the voluntary hospitals-neither public nor private, outside and above government and market, driven neither by politics nor by profit, focused steadfastly on community missions, community service, and community needs. Although government programs of health coverage and commercial health insurers have come to dominate the scene, the old moral halo of voluntarism arguably persists in constraining attempts to impose supra-community, not to say national, standards on health insurance practices in the United States.

The voluntary sector shows up prominently, moreover, in health policy spheres well beyond that of insurance coverage and plays roles much more current and compelling than that of waning historical inspiration. This paper examines a case in point: the marshalling of voluntary organizations in the design and implementation in the Active Living by Design (ALBD) program, a venture in health promotion by means of which the Robert Wood Johnson Foundation sought to encourage changes in the built environment that are conducive to "active living".

Active Living and Health Promotion

The reason why public policymakers and private foundations might concern themselves with the built environment and its propensities to encourage or inhibit physical activity is not obscure: a range of evidence indicates that regular physical exercise can help to prevent or ameliorate health problems such as cancer, cardiovascular disease, osteoporosis, diabetes, and dementia (Brody, 2010, p. D7). Although these benefits may correlate with weight reductions, they appear to work largely independent of weight loss and therefore are a far more plausible objective of health promotion than “anti-obesity” campaigns per se (Oliver, 2006).

Alas, as modern societies moved from physically demanding agricultural and manufacturing jobs to service work, usually more sedentary in nature, activity became a less active ingredient in the course of daily lives, and the advent of labor-saving technologies reinforced this trend. Many Americans now jump in their car, commute to work, sit at a computer, drive home, and then decompress in front of a television or home computer, munching on junk food snacks all (or some of) the while. (Oliver (2006) notes that snacking now gives the average American the caloric equivalent of four meals a day.) Although economic and technical change account for some of this pattern, the built environment-the design of roads, sidewalks, residential areas, and downtowns-deters people who might be inclined to walk or bike to work or shop if the prospect were more appealing. The built environment, in short, deserves a place on the list of social determinants of health-perhaps not so prominent a place as (say) income distribution, but a conspicuous place nonetheless.

Active Living by Design

In 2001 the Robert Wood Johnson Foundation decided to address the built environment. The Active Living by Design program, designed by M. Katherine Kraft, then a project officer at the foundation, awarded small grants to communities that devised innovative and plausible plans to launch or refine programs and policies that would make their physical infrastructure more conducive to walking, biking, and exercise. The Foundation’s request for proposals struck a responsive chord. From an enormous number of letters of intent, the foundation solicited formal applications and finally chose to fund 25 communities. The vignettes offered here, drawn from an evaluation conducted by the author, draw on four funded sites-Louisville, Kentucky; Wilkes-Barre, Pennsylvania; Albuquerque, New Mexico; and Sacramento, California. The evaluation is based on a review of documents depicting the aspirations and activities of the sites and on two sets of in-person, on-site interviews conducted by the author, the first in 2008, the second in 2010.

The Social Sector and the Built Environment

The built environment is a product of private sector development patterns unfolding within a framework of arcane public laws and rules that govern planning, zoning, building, siting, emission reductions, mixing of “uses”, and much more. These private-public production functions would appear to squeeze out roles and functions for the third “social” sector of community-based voluntary organizations, but in ALBD such entities proved to be surprisingly important in persuading the two “primary” sectors to cooperate in pursuit of changes in the built environment that enhanced occasions for active living. There seems to be no altogether adequate term that captures these roles and functions-facilitator, catalyst, glue-get at some of it, but none of these is quite right. The palpable contribution of the social sector to the innovations the ALBD program sought emerges clearly, however, from a quick look at the four above-mentioned sites.

Louisville, Kentucky

In Louisville, a city of 256,000 people within a metropolitan region of 1.4 million, the ALBD grant was linked to a “Hope 6” program, funded by the U.S. Department of Housing and Urban Development, which funded renovation and new construction of public housing in low-income neighborhoods near the central business district. A link between the HUD and RWJF grants, city officials surmised, would simultaneously advance goals for better housing and better health for a population much in need of both. When they presented their plans, however, ALBD staff were surprised to find that residents of the community had decidedly mixed feelings about the encouragement of walking and biking. Crime and safety were paramount issues: areas becalmed from traffic might invite criminals, and the prospect that walkers and bikers might encounter drug dealers, youth gangs, and other threats much enhanced the appeals of staying home.

Apprised that "middle class" assumptions about walking and biking did not automatically translate intact for lower-income communities, the ALBD planners turned for council to the Presbyterian Community Center, a social service organization so well-established and highly regarded that it was commonly called the "gatekeeper" for communications between city officials and the communities it served. Discussions between the PCC and ALBD staff led in turn to negotiations with the city's police department as to how safety improvements could be incorporated into plans to encourage physical activity amid the Hope 6 sites.

Wilkes Barre, Pennsylvania

Wilkes-Barre, a city of 41,000 in a metropolitan area of 550,000, is a hard- pressed former center of coal transport, the downtown of which lies along the flood-prone Susquehanna River and is the object of ambitious redevelopment plans launched by the business community. These plans entail not only the construction of walking and bike paths along the river, to which residents and workers downtown have ready access, but also the extension of, and connections among, the abundant trails in the Greater Wilkes Barre area and throughout Luzerne County-an attraction not only to residents but also to tourists and those contemplating a move to the area for work. To ALBD staff and their supporters in the business community, then, active living and regional and downtown redevelopment can and should be mutually supportive.

The central aims of ALBD in Wilkes Barre were the construction, extension, connection, and "social marketing" of trails. Federal, state, and county funds could sometimes be found to support construction and extension, but budgeting for operation and maintenance was a challenge. To raise funds and secure volunteers to keep the trails in good shape (clear, safe, and devoid of surface irregularities that might cause falls and trigger lawsuits), ALBD turned to trail associations-voluntary organizations of people who "adopted" individual trails, canvassed public agencies for (scarce) funds, raised money by means of pizza parties and other enjoyable events at which games were played and prizes awarded on behalf of trails (in the world of active living fun is a critical, if not the indispensible, incentive), secured free time and space in the media to raise awareness of trails and the opportunities they offer, and, not least important, helped with the physical labors of maintaining them. None of this was easy: the work depended on a small number of activists whose organizations competed for small and shrinking pools of funds that seldom covered basics of organizational maintenance such as staff salaries and office space. Nevertheless these "social" entities were crucial to ALBD plans to link creative public land use and downtown redevelopment in the service of active living.

Albuquerque, New Mexico

Whereas Wilkes-Barre fears floods, Albuquerque (a city of 500,000 in a metropolitan region of 846,000) needs water. A classic exemplar of Southwestern sprawl, Albuquerque houses an aged downtown under (gradual) redevelopment; an assortment of neighborhoods, some of which (for instance, Nob Hill, near the University of New Mexico campus) are fairly conducive to walking and biking, and others (lower income communities) are not; and a periphery of sprawling new developments in which an annual income of (say) $40,000 might (at least before the economic collapse of late 2008) support a mortgage on a sizable house with yard, garage, and (absent "mixed" use) a drive of several miles to buy a quart of milk or other daily necessities. Cultural barriers inhibit denser development and other deterrents to the constant use of automobiles on which the objectives of ALBD depend. Residents want to see the mountains, not the neighbors. The former mayor famously remarked that the only thing the denizens of Albuquerque hate more than sprawl is density. Private developers are financially and politically influential. City planners and private activists work to change the picture but face long odds.

Albuquerque, however, contains a contingent of articulate residents who worry about the future adequacy of water supplies, protection of the environment, the effects of automobile emissions on global warming, and kindred concerns. When ALBD took shape in the city, the principal organizational voice on these "sustainability" issues was 1000 Friends of New Mexico, an advocacy group that eclectically combined elements of Smart Growth, New Urbanism, and other persuasions unfriendly to sprawl; supportive of dense, mixed land use; and therefore receptive to ALBD's plans to encourage more walkable streets, bike lanes, and

"Great Streets", reminiscent of the walkable neighborhoods of European cities-or, for that matter, Sante Fe. Ensconced at 1000 Friends, ALBD staff worked to tip the balance in local debates-to change the "vocabulary", as one activist put it-and gradually gained ground in master plans, zoning codes, subdivision ordinances, manuals for the design of housing developments and transportation projects, decisions of local municipal review committees, and, not least important, the ranks of the city council. Although success has been decidedly incremental, it is noteworthy that when 1000 Friends succumbed to budget troubles in hard fiscal times, the city council itself assumed formal sponsorship of the ALBD grant in its waning months.

Sacramento, California

Sacramento, a city of 500,000 people in a metropolitan region of 2.1 million, is the capitol of California. Like Albuquerque, it is sizable and (at least before the economic downturn of the late 2000s discouraged new construction) fast-growing and inclined to sprawl along its (sub) urban fringes. It differs from Albuquerque, however, in two respects of major importance for the ALBD agenda. First, Sacramento has long housed a well-organized and energetic coalition of bicyclists, who teamed in ALBD with an increasingly formidable organization of pedestrians (Walk Sacramento). Second, the state of California (unlike New Mexico) has been aggressive in seeking to curb emissions from automobiles and has enacted an imposing framework of state laws that constrain the decisions of county and local policymakers and transportation and zoning officials. This supply of regulations created policy space, so to speak, for the demands of ALBD activists, who argued that a built environment better geared to the needs of walkers and bikers produced both cleaner air and better health.

Sacramento's ALBD protagonists not only pursued a familiar agenda calling for wider and better connected sidewalks and bike lanes and "Complete" streets (ones easily navigable on foot and bike and containing a mix of residential, commercial, and recreational activities), but also had uncommon success with a strategy widely discussed elsewhere but seldom much advanced, namely, safe routes to school. In Sacramento, bicycle advocates with unusual political sagacity and energy explained to parents how their children might walk or bike to school along well-organized and monitored routes without falling foul of dangerous traffic or "stranger danger", and worked hard to win support (and federal and state money) for safe routes among teachers, principals, and the superintendent of schools.

Vignettes of Voluntarism

These glimpses into the complex ends and means of four ALBD cities are too glancing to be definitive on any count, but they arguably illuminate the workings of voluntary forces and "social" organizations in a policy milieu too quickly depicted as driven mainly if not solely by the private and public sectors. The four communities introduced here shared a common goal-promotion of health for their populations-and a common means to that end-changes in the built environment that encouraged active living. Each of the four sites displays its particular variation on this means/ends theme, and the variations vary impressively. But common to all four are the signal contributions of voluntary organizations working as "enablers" that forge some degree of new cooperation between public and private actors in support of positive changes in the built environment. To be sure, the changes in question are to date mainly marginal, a policy toehold that may or may not persist and progress. Time alone will tell what the ALBD program accomplished, and the evaluation on which this discussion draws comes too soon, as evaluations generally do. All the same, the constant and constructive presence of community organizations, trail associations, sustainability advocates, and coalitions of bikers and walkers as networkers (less "issue" networkers in Heclo's (1978) sense than "project" networkers) serves to remind policy analysts that the works and ways of the public and private sectors are rarely the whole story behind social change.

This testimony to the contributions of the third sector as a "change agent" is perhaps inspiriting, but reliance on voluntary organizations in pursuit of policy innovations also has its costs. These entities are often marginal players, thinly staffed, meagerly funded, and maintained by small membership bases. That the membership is intensely committed cuts two ways: it drives the groups to make prodigious exertions, but also fuels bitter quarrels within the activated groups and between them and other organizations working the same or similar turf. (Bikers and pedestrians, or example, may contemplate the built environment from quite distinct perspectives.) Such associations are hard to sustain, and so too therefore are their projects and the lobbying work that fortifies them. They compete with each other locally and nationally for philanthropic dollars and public grants. And they stand accountable neither to voters nor to shareholders. In bygone days the institutional position of the third sector beyond both politics and profit, “above” government and market, conferred legitimacy by painting a moral superiority grounded in a disinterested community mission. Nowadays the virtues of voluntarism appear rather less pristine and the sector's attenuated accountability is rather more prominent.

In the highly contemporary mini-cases sketched here, however, the role of social organizations as institutional enablers and project networkers was valuable, arguably invaluable, in getting government and market into a productive dialogue on how the built environment might be reshaped in ways that reflect evolving notions of the public interest in health promotion by means of active living. Though weakly accountable themselves, these groups helped to instill accountability into sectors that might otherwise have declined to give as much time and attention as in fact they did to the goals of ALBD. Accountability works in mysterious ways.

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The Role of Regional Health Improvement Collaboratives in Health Policy, USA

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Introduction

Regional, multi-stakeholder health improvement collaboratives emerged in the United States in the 1990s in part to address employers' concerns about the high cost and disappointing performance of the health care purchased on behalf of American workers. Bringing together business and civic leaders, insurers, healthcare providers, and users of healthcare services, the coalitions work to improve the safety, efficiency, and quality of health care by engaging in public reporting to inform consumer choice, piloting disease prevention programs, and launching quality improvement initiatives. Founded in 1997, the Pittsburgh Regional Health Initiative (PRHI) illustrates the history and role of these coalitions in shaping the U.S. healthcare landscape. As an early leader and ongoing innovator, PRHI has focused on quality improvement in healthcare settings, utilizing its own quality improvement methodology – Perfecting Patient CareSM. It has, for example, achieved dramatic success in efforts to eliminate healthcare-acquired infections, to improve the delivery of primary care, and to integrate care across settings in order to improve outcomes for patients managing chronic disease. In recent years, PRHI, along with other collaboratives, are playing key roles at the regional level – and increasingly in cooperation with one another at the national level – experimenting with approaches to payment reform, supporting federal efforts to expand the use of health information technology in primary care, and spreading best practices more rapidly throughout the U.S. healthcare system. Regional health improvement collaboratives (RHICs) like PRHI appear to be a unique and growing fixture in the U.S. healthcare landscape with the potential to transform healthcare delivery. Using PRHI as a model, this paper describes the unique role that regional, multi-stakeholder health improvement collaboratives continue to play in transforming United States health care.

The Emergence of Regional Quality Improvement Initiatives

As evidence mounted in the 1990s regarding poor care at the front line and waste in the healthcare system, new change agents appeared on the U.S. healthcare scene. The new regional multi-stakeholder collaboratives were often driven by regional business leaders who recognized that they were not buying value. This was all the more troubling given their unique role as purchasers of employee health insurance and therefore "gatekeepers" to health services for much of the U.S. working population. Leading businesses recognized that public policy solutions were largely not on the agenda and those that were seemed unlikely to get the job done. Consequently, in communities throughout the United States, business and civic leaders, insurers and healthcare providers, and users of healthcare services began to organize to see what could be done at the regional level to achieve value (Mosser, Karp, & Rabson, 2006). Several applied an axiom more common to the world of commerce – that *value* in health care, as in business, could be achieved by reducing waste and managing costs. Initially the goals of the new collaboratives depended on a constellation of regional attributes, but generally coalesced around the following:

- Public reporting,
- Quality improvement, and
- Disease prevention, such as diabetes outreach and education.

Many of the initiatives were established with grants from federal sources as well as private insurers to create transparency in the healthcare marketplace through public reporting of quality data in the hopes that informed consumer choice would drive value. Public reporting, therefore, formed the core of many of the early collaboratives. PRHI, in part because statewide quality data already existed through the Pennsylvania Health Care Cost Containment Council, focused on quality improvement. Others, recognizing that caring for those with chronic disease constitutes a large portion of health care expenditures, focused on disease prevention. Despite differences in emphases, a quest for savings and more efficient care, i.e., value, unite all of the RHICs.

Notably, however, issues around health insurance coverage are absent from these core strategies. In areas such as Boston and Pittsburgh, other organizations, such as consumer health organizations, have focused on coverage. In addition, some collaboratives, including PRHI, worked closely with community health centers, a critical point of access to care for those without insurance.

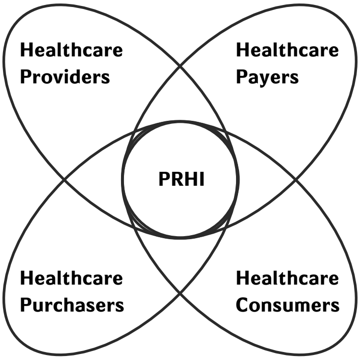
There are two primary articles regarding quality improvement organizations to date. The first, published in 2003 by the RAND Corporation, is a collection of case studies of four collaboratives, all at different periods in their life cycle (Farley, Haims, Keyser, Olmsted, Curry, & Sorbero, 2003). By analyzing these four organizations (PRHI was one of the collaboratives studied), the authors were able to identify important issues related to sustainability and effectiveness. The article identified a number of key factors for success, including: "strong leadership; broad-based community commitment; availability of financial resources and incentives; adaptability and flexibility; dissemination of credible, objective, and actionable data-driven information; physician leadership in initiative development; establishing the motivation and active involvement of major providers; achieving measurable outcomes of improvement; and managing the various facets of growth and expansion" (Farley et al., 2003, p. xvi).

More recently, as part of the planning process for and launch of the Network for Regional Healthcare Improvement (a coalition of RHICs founded in 2004), researchers funded by the Robert Wood Johnson Foundation defined RHICs as nonprofit organizations, constituted by member organizations, working to improve the health and healthcare in their communities and limited to a defined geographic area (Mosser et al., 2006). The paper explains that among the important benefits of a regional coalition are: (1) providing a framework for cooperation, (2) responding to the unique sensitivities of the region, and (3) establishing the community expectations for quality (Mosser et al., 2006).

The authors also note some of the key challenges to effective implementation of public reporting and quality improvement engagement, pointing out the challenge of balancing the sometimes competing interests of consumers, employers (who purchase most U.S. health insurance), and physicians (Mosser et al., 2006). In short, RHICs are often both watchdogs for consumers and mentors to providers attempting to improve quality. Not surprisingly, RHICs often find it challenging to fully engage health system leadership and clinicians in committing to system-wide quality improvement (Mosser et al., 2006).

Building on these previous papers, this paper illustrates the history and role of RHICs by focusing on the efforts of one of the earliest models, the Pittsburgh Regional Health Initiative (PRHI). It describes PRHI's early successes at catalyzing improvements in healthcare quality in hospital care. It also describes the awareness, growing out of years of demonstration projects, that the barriers to improving care are multi-dimensional and require a willingness to improve work in multiple care settings often not amenable to change. This awareness has shaped PRHI's more recent work focused on care integration, payment reform and redesigning the care delivery structure.

Figure 1: *PRHI Stakeholders.*



These roles simultaneously require regional experimentation and national policy advocacy, prompting many of the approximately 50 RHICs around the country to work even more closely with one another collaboratively. The organizations guiding these efforts include the Network for Regional Healthcare Improvement, founded in 2004 (2010); The Robert Wood Johnson Foundation's Aligning Forces for Quality program, founded in 2006 (see http://www.rwjf.org/qualityequality/af4q/about.jsp); and the Agency for Healthcare Research and Quality's Chartered Value Exchanges, founded in 2008 (see http://www.hhs.gov/valuedriven/communities/exchanges.html).

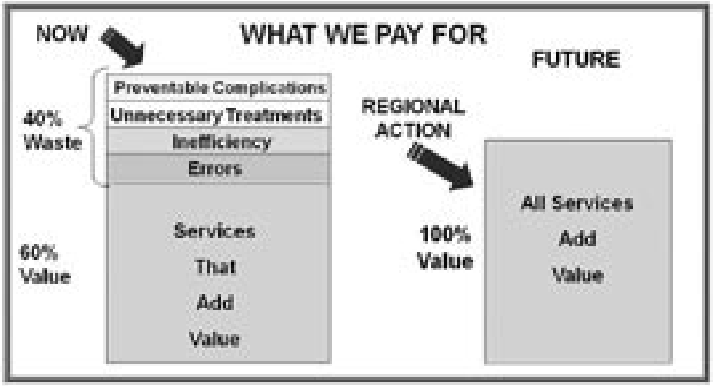
An Early Innovator: The Pittsburgh Regional Health Initiative

The Pittsburgh Regional Health Initiative (PRHI) was among the first such regional multi-stakeholder health improvement collaboratives formed to reduce cost by improving the quality, safety, and efficiency of health care. Founded in 1997 as a nonprofit, supporting organization of the Jewish Healthcare Foundation, PRHI (led by business and civic leaders, healthcare providers, insurers, purchasers, and consumers) focused on the second goal mentioned above – quality improvement.

Guided by its mission to be an independent catalyst for improving healthcare safety and quality in southwestern Pennsylvania, PRHI operated on the premise that dramatic quality improvement is the best cost-containment strategy for health care. PRHI was the first regional collaborative to address healthcare safety and quality improvement as both a social *and* a business imperative.

PRHI's vision is that, by eliminating waste, patients can expect better care (i.e., better health) at a lower cost (see Figure 2). Waste, as current research has shown, is pervasive in the U.S. healthcare system. One study estimated that waste may add up to as much as $850 billion per year, stemming from: inefficient adminstrative systems ($100-$150 billion), provider inefficiency and errors ($75-$100 billion), lack of care coordination ($25-$50 billion), unwarranted use ($250-$325 billion), preventable conditions and avoidable care ($25-$50 billion), and fraud and abuse ($125-$175 billion) (Kelley, 2009).

Figure 2: *Waste and Value in the Healthcare System.*



Our region is by no means immune from these trends. For example, the Pittsburgh region has the third highest number of preventable hospital admissions, according to Medicare data on discharges for Ambulatory Care-Sensitive Conditions per 1,000 Medicare enrollees (The Dartmouth Atlas of Health Care, 2009). Hospital admissions are far more costly than even intense outpatient treatment. Not only are hospitalizations among the most expensive form of health care, but inpatient stays increase the risk of acquiring healthcare-associated infections, harming the patient and further driving up costs.

Four core principles guide all of PRHI's work to increase value in health care:

1. Improving healthcare quality reduces costs.
2. Health care is local; federal policy changes alone cannot achieve needed reform.
3. Those who work at the point of care develop quality and safety improvements that work.
4. Continuous improvement in quality and safety requires the highest possible standard, namely perfection; to settle for less limits achievement.

Perfecting Patient Care^{SM}

To achieve its vision, PRHI developed its own quality improvement method called Perfecting Patient *Care^{SM}* (PPC), derived from Lean methodology. PPC University (a four-day learning experience) and on-site PPC coaches with expertise in problem-solving provide healthcare professionals with the training, tools, and support they need to achieve the highest value patient care.

Together with its healthcare partners, PRHI has successfully demonstrated the power of PPC to deliver safer, more efficient, and proven care, simultaneously. Nearly 2,000 people, including doctors, nurses, pharmacists, administrators, and technicians, have received PPC training. While the majority of the participants have come from facilities in the Pittsburgh region, trainees increasingly come from outside the region and have included representatives from 26 states, 267 organizations, 137 hospitals and practices, and 9 insurers.

Most of the early applications of PPC training took place within hospitals – focusing on reducing healthcare-acquired infections, reducing pathology lab error rates, and increasing employee retention. For example, a unit at the Veterans Administration Pittsburgh Healthcare System (VAPHS) hospital was an early adopter of PPC and targeted MRSA infections. Led by a PRHI staffer who was an engineer, and by a respected VAPHS nurse, the unit began to solve problems methodically, one by one, making it easier for workers to observe known guidelines, such as hand hygiene, gloving, and gowning. Over a three-year period, the unit posted an 85% decline in MRSA rates, according to an outside evaluation by the U.S. Centers for Disease Control and Prevention. This work led to revised policies in the VA system throughout the United States (Pittsburgh Regional Health Initiative, 2008, p. 12).

Similarly, using PPC training, in 2005 a local pathologist, Stephen Raab, MD, PhD, and his colleagues began applying its basic principles in a hospital pathology lab. The results were widely published, describing how Raab and his team achieved faster specimen processing and, in the case of Pap smears and thyroid biopsies, improved communication with surgeons and physicians, yielding better results for patients (Condel, Sharbaugh, & Raab, 2004; Raab, Andrew-Jaja, Condel, & Dabbs, 2006b; Raab et al., 2006a, 2008a, 2008b).

Finally, in addition to improving patient outcomes by minimizing errors, improving efficiency, and lowering cost, PPC methods have increased employee satisfaction. By eliminating wasted time and resources, staff finds the time needed to meet patient needs. Importantly, staff retention correlates with the quality, safety, and efficiency of the work environment. Take, for example, one of PRHI's demonstration projects: Simply leveling the work load among nurses in an organ transplant unit helped to reduce staff turnover from 12 percent to zero and to generate savings of nearly $900,000 in the first year (Pittsburgh Regional Health Initiative, 2008, p. 31).

Over time, PRHI expanded the application of these quality improvement methods outside of the hospital to include skilled nursing facilities and community primary care providers, garnering similar results. It was clear that the method was effective in nearly every healthcare setting in which it was applied. For a comprehensive list of PRHI-led demonstrations, please see Appendix Table 1.

Expanding Beyond Single Focus Approaches

PRHI demonstrated the power of applying quality improvement methods developed by manufacturers to healthcare delivery in a variety of care settings. Nevertheless, over time, the recognition dawned that there were problems that even an excellent quality improvement method could not fix. First, there were, and continue to be, financial incentives for delivering poor care, and few disincentives to poor performance. Second, the savings achieved with improved care accrue to the insurers and not to the healthcare providers actually achieving quality improvement. Finally, improvements in one part of a hospital are rarely applied elsewhere in the same institution, prompting a PRHI quip that "The only thing that does not spread in health care is quality."

PRHI, and regional collaboratives around the country increasingly recognized that, in the face of complex barriers, a quality improvement strategy alone would be inadequate to achieve the needed repair. Other regional collaboratives similarly recognized that consumer reporting strategies or disease prevention strategies alone will not improve value significantly. All began to reach the same conclusion: a multi-faceted approach, exemplified by Figure 3, is essential: Unless a health system hits all the notes on the "Xylophone of Quality", it will not succeed in becoming a high value care system.

Figure 3: *Xylophone of Quality.*

Hitting some of the “notes” – such as effective and pervasive health information technology (HIT) – will require extra-regional involvement; indeed, the federal government has been playing a lead role to advance HIT in U.S. health care. In 2004, the Bush Administration created the Office of the National Coordinator for Health Information Technology (ONC) in the Department of Health and Human Services to support the adoption of HIT and promote information exchange to improve health care. Similarly, the Centers for Medicare & Medicaid Services (CMS) launched a demonstration project to encourage small- and medium-size physician practices to adopt electronic health records (EHRs). Pursuing a similar agenda, the Obama Administration has directed enormous resources to improve HIT via the American Recovery and Reinvestment Act of 2009. In all cases, regional multi-stakeholder health improvement collaboratives play central roles. For example, RHICs are responsible for organizing the CMS EHR Demonstration. Further, a recently announced Beacon Community Cooperative Agreement Program will provide $220 million in funding to 12 communities to build and strengthen their HIT infrastructure and exchanges (Office of the National Coordinator for Health Information Technology, Department of Health and Human

Services, 2009). Successfully implementing the Beacon program will require multi-stakeholder leadership and cooperation.

Regional Initiatives Continue to Lead the Way

In this new environment, collaboratives continue to lead regionally, as well as nationally, in the “quality improvement” space. At the regional level, collaboratives are engaged in pilot projects that test approaches to adding value by encouraging greater care management and integration. These include programs working to better integrate hospital and community-based care, as well as programs that aim to strengthen and broaden primary care.

Many of the programs are regional efforts to address issues that seem intractable at the national level. As shown in Table 1, some of the most innovative ideas related to healthcare reform, including pay for performance, medical homes, episode/bundled payment, and total cost accountability, have gained more traction as a result of state and local initiatives rather than national programs (Miller, 2010a).

Table 1: *Local versus national action in healthcare innovation.*

	STATE & REGIONAL COLLABORATIVES	CONGRESS/ MEDICARE
Pay for Performance	Most regions and insurers have some form of P4P for hospitals and/or MDs	Still thinking about it
Medical Homes	Major initiatives underway in CO, MA, ME, MI, MN, NC, OR, PA, RI, VT, WA & others	Started a demonstration project, then stopped
Episode/ Bundled Payment	Initiatives beginning in Minnesota, Rockford (IL), Pennsylvania, Utah, others	Cardiac Demo in 1990s not expanded; new demo started in 2010
Total Cost Accountability	Initiatives in place or being developed in MA, ME, MN, Medicaid	Shared savings demos with large physician groups

Source: Miller (2010b)

The reason that most creative reforms are being tested at the regional level is best understood as the result of three unique characteristics of RHICs: (1) community leadership and engagement on quality, (2) objectivity that comes from little or no financial incentive within the healthcare system, and (3) the ability to bring pieces from the entire healthcare system together.

Community Leadership and Engagement on Quality

By definition, RHICs engage stakeholders throughout the healthcare system, including insurers, consumers, providers, and employers, and raise the expectation for improvement. Mosser et al. find that creating the community expectation that certain levels of performance are unacceptable and that performance can and should improve is a key benefit of regional collaboratives (Mosser et al., 2006). This community expectation can help apply the needed impetus for a renewed engagement on issues of quality and overcoming a multi-dimensional apathy among insurers and consumers. Even when quality improvement efforts are clearly beneficial, insurers and consumers have been notably apathetic to calls for improved quality.

An Objective Partner

One of the greatest strengths of RHICs is their ability to act as an outside, objective partner without financial incentives to continue the status quo. One might expect that large healthcare systems or progressive hospital associations might also spearhead these improvement efforts. Unfortunately, the fee-for-service financing and payment system in the United States penalizes providers for improved care that eliminates errors, waste, redundancy, and infections. A PRHI analysis in 2007, published in Modern Healthcare, found that hospitals actually made money when patients developed infections while in the hospital (Becker, 2007). In part because of these perverse incentives, it often takes an outsider to instigate changes to improve quality. Regional collaboratives are in the position to essentially say, "Let's do what is right, moral, and honorable and give people the best care even it if costs money at first."

Putting the Pieces Together

As mentioned, one of the important roles of RHICs is to bring many if not all of the stakeholders together. Healthcare in the United States needs to be reformed at nearly every level, redefining relationships between all of the key partners. Payment, delivery, workforce, incentives and rewards, health information technology, and measurement are all on the table. Why? Because delivering the right care, to the right person, at the right time, at the right price requires just such a transformation in health care. No single stakeholder can put all of these pieces together to weave a cohesive quality improvement program. Collaboratives, on the other hand, not only include members working in all of these areas, but have also often developed deep expertise in all of these areas.

PRHI's Delivery System Programs

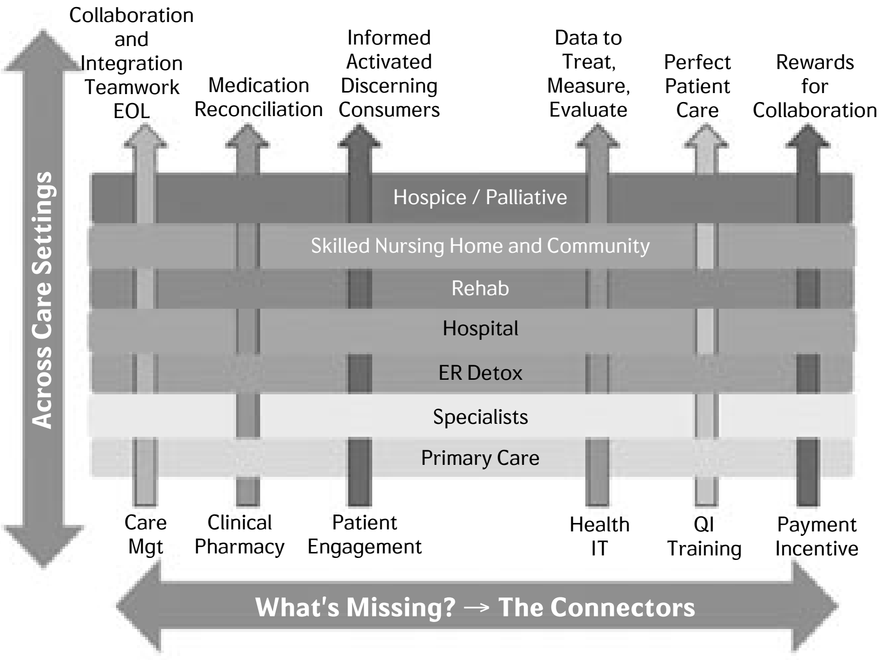
PRHI stands as a leading example of quality improvement collaboration and pilot testing across care settings. Below are brief descriptions of PRHI initiatives, each of which has engaged insurers, providers, and consumers to achieve its goals.

Scalable and Sustainable Care Management and Integration

PRHI has increasingly focused on new directions for care integration. Studies have shown that gaps in healthcare quality can be attributed to poor care coordination and faulty transitions of care. Driven by a fee-for-service system that rewards overuse of costly specialized services and involvement of multiple physicians in the treatment of individual patients, frequent – and often preventable – hospitalizations and re-hospitalizations of patients with chronic disease have become the norm. Not only is the resulting care not meeting patient needs, but staggering healthcare costs are traceable primarily to the volume of inpatient care delivered to patients with chronic diseases.

Reimagining this situation, PRHI has depicted health care like a tapestry (see Figure 4), in which all services are woven together to form a cohesive whole. In this model, essential, cross-cutting services would be reimbursable because they have the potential to significantly improve patient care. These services include care management, clinical pharmacy (especially medication reconciliation), patient engagement, health information technology, and quality improvement training.

Figure 4: *Healthcare Tapestry.*



This tapestry especially targets chronic disease management as an important opportunity to reduce costs. With appropriate primary care and care management, the number of acute episodes can be reduced, significantly lowering the costs of caring for these diseases. PRHI has been involved in multiple initiatives that demonstrate alternative ways to achieve integration.

Informing these initiatives is a solid research base. PRHI is leveraging regional, all-insurer hospital admission data from the Pennsylvania Health Care Cost Containment Council to identify patterns of hospital admissions and readmissions that reveal opportunities for improvement. Often, patients enter hospitals when appropriate care is not provided at the right time and in the right setting. PRHI is looking for just these fault lines to better target its community and primary care initiatives.

The Readmissions Reduction Initiative

The benefits of integrated care are both real and impressive. Two years ago PRHI undertook a chronic obstructive pulmonary disease (COPD) hospital readmission reduction project. Funding was secured to hire dedicated COPD care managers to work out of two large primary care practices with tight affiliations to two community hospitals. PRHI Lean Healthcare coaches helped the hospitals and providers refine clinical pathways using Perfecting Patient CareSM methods. This project utilized enhanced communication within the hospital and between hospital and affiliated primary care practices, medication reconciliation and home visits to drastically reduce hospital readmissions for patients admitted with COPD. Within one year one hospital was able to cut its 30-day readmission rates for COPD by half, an accomplishment which has been sustained (Miller, 2010b).[1]

Accountable Care Networks

Accountable Care Organizations (ACOs) have been widely proposed as a means through which delivery and payment can be realigned, achieving the goal of improved integration of care (Fisher, Staiger, Bynum, & Gottlieb, 2007). ACOs are formally organized clusters of hospitals and physicians integrating patient care across all settings, with financial incentives based on shared accountability for quality and patient outcomes. ACOs represent a path for reform that builds on current provider referral patterns and offers shared savings payments to communities of providers willing to be held accountable for quality and costs. Accountable care concepts are appearing in virtually all of the proposed healthcare reform draft legislation, and several pilots have already been launched in Roanoke (Virginia), Tucson (Arizona), and Louisville (Kentucky).

To advance the concept regionally, PRHI envisioned the accountable care *network* (ACN) as an intermediate step towards an ACO. While ACOs formalize the relationship between hospitals and physician offices including shared payment, ACNs call for a transition stage where providers in different levels of care within a geographic area demonstrate their ability to work in collaboration in the prevention and management of disease. This is a first step in taking on financial risk for the overall

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[1] For more information, see: http://www.prhi.org/FineAwards/2009/Fine_2009_Silver.html

outcomes of care for a distinct population. PRHI is engaging two community hospitals and their affiliated primary care practices to form ACNs around a coordinated readmission reduction program, building on the successful COPD readmission reduction project.

The Safety Net Medical Home Initiative

The Safety Net Medical Home Initiative (SNMHI) is a four-year project to develop and demonstrate a replicable and sustainable implementation model for transforming safety net providers (community health centers) into patient-centered medical homes (PCMHs). The PCMH model has been shown to improve patient outcomes, quality of care delivery, and patient and staff satisfaction by enhancing the patient-care team relationship, streamlining transitions of care, and providing a more holistic approach to primary care delivery (Rosenthal, 2008). With support from the Commonwealth Fund, PRHI is providing technical assistance, in the form of practice coaching, to 10 partner health centers, as well as coordination of an advisory group and learning collaborative working groups. The health centers, in turn, will seek formal designation as PCMHs by meeting criteria set forth by the National Committee for Quality Assurance (NCQA).

Integrating Treatment in Primary Care

Recognizing the prevalence of co-morbid behavioral health problems, particularly in patients managing chronic health problems, PRHI has been working to integrate behavioral health screening and initial treatment in primary care settings. The Integrating Treatment in Primary Care Project is working with three primary care sites to demonstrate the impact of using three evidence-based models of care: Screening, Brief Intervention and Referral to Treatment (SBIRT) for unhealthy substance use, Improving Mood and Promoting Access to Treatment (IMPACT) for depression, and the Chronic Care Model (CCM) for managing the care of patients with chronic disease.

Enabling Small Primary Care Providers to "Meaningfully Use" HIT

Small primary care practices may be the least equipped to adapt to the changing healthcare environment, including, but not limited to, the adoption of electronic health records. PRHI, through the Transforming Care in Provider Practice training modules and practice coaching, is reaching out to hundreds of practices to transform their operations by adopting new technology and more efficient processes. Training modules include: implementing electronic health records, engaging in continuous process improvement, building transformational teams, and improving chronic disease management. In addition to these interactive modules, PRHI is partnering with the region's largest local insurer to provide practice coaching to help sustain these improvements.

Tomorrow's Healthcare™: Meeting the Challenge of Spreading Change

While national political and policy change has the potential to improve the incentive structure of health care, PRHI has embarked on a parallel effort to improve the delivery of care by spreading the PPC methodology and other educational materials through online technologies. Tomorrow's Healthcare™ (THC) is a dynamic, web-based portal that is designed to guide institutions through whole organization transformation by teaching, supporting, recording, rewarding, and sustaining quality improvement and work redesign in healthcare settings. Tomorrow's Healthcare™ combines, for the first time in a single site, quality improvement tools, methods, education, data tracking, professional networking capabilities, and human resource management mechanisms to streamline, standardize, and simplify the way organizations and practices engage in quality improvement. THC is at the forefront of a movement for patient-centered healthcare that is grounded in collaboration, transparency, process redesign, and accountability.

Regional Collaboratives Coalescing

By illustrating key PRHI activities since 1997, this paper describes the unique role that regional, multi-stakeholder health improvement collaboratives continue to play in transforming U.S. health care. There are now more than 50 regional collaboratives in the United States working to address the key challenges facing health care today (see Appendix Maps A and B), many with the proactive support of the Robert Wood Johnson Foundation's Aligning Forces for Quality program[2] and the U.S. Department of Health and Human Services' Chartered Value Exchange (CVE) program.[3] These RHICs design and implement programs that test important concepts required to transform the U.S. healthcare system, including:

- Showing how EHRs can improve care;
- Testing new payment models;
- Disseminating public reports on the quality and cost of physicians, hospitals, health plans, and other healthcare providers;
- Reporting comparative data on the cost and quality of providers for different interventions;
- Showing that reducing healthcare-acquired infections is possible; and
- Improving care for people with chronic diseases.

Despite impressive work at the regional level, in recent years there has been recognition that the scale of needed innovation will need to be aided by coordinating regional efforts and rapidly sharing lessons learned at the regional level. Toward this end, PRHI, along with its parent organization, the Jewish Healthcare Foundation, and six other regional collaboratives, with support from the Robert Wood Johnson Foundation and the California HealthCare Foundation, formed the Network for

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[2] For more information see: http://www.rwjf.org/qualityequality/af4q/index.jsp

[3] For more information see: http://www.hhs.gov/valuedriven/communities/valueexchanges/exchanges.html

Regional Healthcare Improvement (NRHI) in 2004. NRHI is a national coalition of regional collaboratives (now numbering 23) that provides technical assistance to, facilitates information sharing among, and encourages national policies that support efforts by regional health improvement collaboratives to improve healthcare quality and value and advance payment reform (see Appendix *Map A*).

Although regional efforts are powerful, national leadership is still needed. Toward that end, collaboratives have been similarly active at the national level. For example, after the 2008 national presidential election, PRHI developed position papers based on regional surveys regarding health policy reform, especially focused on accountability across levels of care, electronic health records, and patient-centered medical homes. PRHI has also been a vocal advocate for the establishment of a Federal Patient Safety Authority, similar to agencies established for airline and mine safety in the United States.

Critical among issues requiring national leadership are the multitudinous consequences of the way the United States pays for health care, which continues to be an important barrier to safety, efficiency, and quality. Large-scale change envisioned by PRHI requires payment reform that rewards the quality, not quantity, of care; however, the current "fee for service" payment system provides disincentives for hospitals and physicians to coordinate care and avoid inefficiencies in care delivery.

Two NRHI summits held in Pittsburgh in 2007 and 2008 highlighted the fact that much of the care required to improve the quality of life and reduce expensive hospitalizations for people with chronic conditions (who are among the most intensive users of the U.S. healthcare system) is not reimbursable, including patient education, care management, and primary care consultations with specialists. To advance payment reform in a serious way, in 2008 the Jewish Healthcare Foundation funded the establishment of the Center for Healthcare Quality and Payment Reform (CHQPR).[4] CHQPR focuses primarily on the payment reforms necessary to encourage comprehensive, outcome-driven, regionally-grounded approaches to achieving higher value health care.

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[4] For more information see: http://www.chqpr.org/about.html

While acknowledging that there are many issues around which RHICs can work together, at their core, they are local organizations working on local problems with local stakeholders. State laws vary; power dynamics among businesses, providers, and insurers differ; and priorities diverge. This regional variation, combined with differing internal attributes and strengths of the organizations, have helped create a rich variety of programs across the country. This variety, in some ways, adds to the power of the quality improvement movement, as 50 healthcare improvement laboratories continually innovate across the country.

Challenges and Opportunities Moving Forward

Moving forward, RHICs face important challenges. These are briefly summarized below.

Building a Strong Independent National Network to Increase the Voice and Recognition of the Movement

This paper has demonstrated that regional interests in healthcare improvement often converge around needed national-level reform. Toward this end, the past six years have seen the growth of three networks of RHICs – an important step toward garnering the attention of national policymakers. Building on the work of NRHI, collaboratives need to continue to work together to become a more unified voice for safe, quality, and efficient care. Although regional variations require that organizations vary in their means, the core goals remain the same. These goals should be the focus of unity among collaboratives, enabling them to continue to work together.

Managing Diverse and Competing Interests among Stakeholders

As is true for most, if not all, collaboratives, managing diverse interests can be a challenge. Even though all of the stakeholders work to serve the patient, different perspectives emerge, especially regarding the financial interests of individual organizations. As mentioned above, this is often a challenge requiring true dedication on the part of RHIC leadership to maintain neutrality.

Achieving Financial Support for Priority Projects

Ensuring financial stability to enable work on priority projects is a key concern among regional collaboratives that is also related to RHICs' ability to maintain neutrality. Many were started with grant-funding under the assumption that with time, more sustainable funding would arise from member dues, federal contracts, and/or user fees. Farley et al. highlight an important aspect related to financial sustainability: independence. They write, "Successful quality improvement collaborations require funding mechanisms that are sustainable for the long term but do not have an undue effect on coalition objectivity or independence" (Farley et al., 2003, p. xviii). In addition, it is worthwhile to point out that the healthcare environment is continually evolving with new state and federal legislation, advanced clinical and administrative technologies, and changing expectations. To keep up with these changes, it is important for collaboratives to evolve as well. The analysis by Farley et al. found that organizations devoted to one mechanism, e.g., public reporting, found sustainability difficult. Those, however, that continued to expand programs and adapt to the needs of the community might be more equipped to thrive (Farley et al., 2003).

Reconciling Conflicting Roles of Supporting Provider Quality Improvement Efforts and Public Reporting

The mandate of RHICs to expose an organization's or practice's quality indicators at the same time that they help to raise their performance is problematic. RHICs are struggling with this duality and, at the time of this writing, the compatibility of these two roles is unclear.

Conclusion

PRHI and other regional collaboratives have established a national network of concerned stakeholders to defend the thousands of people – both patients and medical professionals, who are individually endangered by healthcare-acquired infections, medical errors, and poor work design – and to contain healthcare spending that threatens long-term economic growth. As regional collaboratives continue to mature and work together, the best practices identified by their innovative demonstration projects will continue to inform and improve U.S. efforts to develop a truly safe, high quality, and efficient healthcare system.

Efforts to reform U.S. health care create new opportunities for RHICs, including: payment reform demonstrations, Accountable Care Organizations' pilots, expansion of federal community health centers, and better end-of-life care. All of these opportunities will require neutral regional coordinating entities to promote, and, sometimes, prepare proposals; build relationships; measure progress; champion new models of care and payment; and promote quality. Patients deserve to have the protections and services to which regional health improvement collaboratives have committed.

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Appendix

Table 1: *PRHI quality improvement demonstrations.*

Topic/Issue	Results
Wheelchairs	Assuring clean, right-sized wheelchair at right time and place enables VAPHS to boost on-time patient transport to physical therapy appointments from 20% to 90+%
Clostridium *difficile* infections	Targeted changes in hospital housekeeping procedures accompanied by 20+% decline in nosocomial gastrointestinal infections
Hospital readmissions	COPD-focused project underway, linking hospital, dedicated care managers, and primary care providers with goal of reducing 30-day readmission rates
Pathology errors	50% reduction in Pap smear tissue sampling defects at one large hospital pathology lab
Nurse turnover/ retention	100% reduction in nurse turnover within abdominal transplant unit ($880,000/yr savings)
ICU early nurse-directed therapy	Average length of stay reduced by 2.2 days, 292.4 total ICU days saved, $1.46 million/yr saved in intensive care unit bed costs
Outpatient diabetes clinic	After one year: 100% compliance with ADA guidelines; 100% documentation; 100% aspirin use (30% national average); improved A1c, LDL, and blood pressure - 3 of 5 patients achieve recommended standards; 20% increase in clinic patient volume
Pediatric autism clinic	17% reduction in patient waiting time
Patient falls	Patient medication, toileting, and mental health circumstances pinpointed as significant contributors; targeted actions reduce falls to zero for months at a time

Timely medication delivery	Re-engineered Rx delivery system enables VAPHS to improve on-time medication delivery from 90% to 99%, eliminating 40-60/late Rx/day
Medication errors and accurate patient identification	New patient identification procedures at community hospital accompanied by medication errors dropping from 7 in 6 mos to just 1 in next 6 mos.
Ambi-Surg center efficiency	New procedures halve patient waiting times, 98.6% of patients arrive in operating room on-time, all patients arrive in OR with lab tests completed
Surgical patient - chart verification	Revamped chart verification system at tertiary hospital reduces defective charts from 30-35/day to nearly zero, saving total of 6 hours of pre-surgical registered nurse time/week
Hospital ER "Code Red" diversions	Rapid-cycle process improvements reduce diversions of ambulances from a busy hospital ER from 180 hours/month to zero; ER patient satisfaction doubles
Pathology lab efficiency	Large pathology lab doubles work load, decreases turn-around time without adding staff

Map A: *Regional Healthcare Coalitions in the United States and Canada.*

Source: http://nrhi.org/

Network for Regional Healthcare Improvement Members

California
- California Cooperative Healthcare Reporting Initiative
- California Quality Collaborative
- Integrated Healthcare Association

Illinois
- Quality Quest for Health of Illinois

Iowa
- Iowa Healthcare Collaborative

Louisiana
- Louisiana Health Care Quality Forum

Maine
- Maine Health Management Coalition
- Quality Counts

Massachusetts
- Massachusetts Health Quality Partners

Michigan
- Greater Detroit Area Health Council

Minnesota
- Institute for Clinical Systems Improvement
- Minnesota Community Measurement

Nevada
- Nevada Partnership for Value-Driven Healthcare (HealthInsight)

New York
- New York Quality Alliance

Ohio
- Health Improvement Collaborative of Greater Cincinnati

Oregon
- Oregon Health Care Quality Corporation

Pennsylvania
- Aligning Forces for Quality
- Pittsburgh Regional Health Initiative

Tennessee
- Healthy Memphis Common Table

Utah
- Utah Partnership for Value-Driven Healthcare (HealthInsight)

Washington
- Puget Sound Health Alliance

Wisconsin

- Wisconsin Collaborative for Healthcare Quality
- Wisconsin Healthcare Value Exchange

Source: Network for Regional Healthcare Improvement (2010)

Map B: *Chartered Value Exchanges.*

Source: Agency for Healthcare Research and Quality